Volume I: Research Component

Experience of caregiving for people with dementia

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OVERVIEW

This thesis contains the work completed as part of a three year Doctorate in Clinical Psychology at the University of Birmingham, UK. The work comprises of two volumes. The first volume covers the research component of the course, whilst the second volume includes clinical practice reports of work carried out during placements within the National Health Service.

Volume I comprises of three papers. The first paper is a systematic critical review of the current literature regarding psychosocial interventions for individuals who are caregiving for a family member with dementia. The second paper presents a quantitative small-scale research study examining the relationship between spousal caregivers' perceptions of the relationship and their experience of caregiving. The final paper of this volume is an executive summary of the main research findings.

Volume II comprises of five clinical practice reports based upon the clinical work carried out during placements in the NHS as a Clinical Psychologist in Training. The first report presents the case of 'Simon' who was experiencing obsessive compulsive symptoms. Simon's difficulties were formulated from two psychological models; cognitive and systemic. The second report is a service evaluation of the Choice and Partnership Approach within a Child and Adolescent Mental Health Service. The third report is a single case experimental design investigating the effectiveness of Cognitive Behavioural Therapy for a 74 year old lady experiencing depression and suicidal ideation and intent. The fourth report is a case study of the work carried out with 'Satbir' a young person with Autism engaging in self-injurious behaviours. The fifth report presented here is in the form of an abstract, and describes a presentation carried out for the case study of 'Sarah' who was experiencing Post-Traumatic Stress Disorder.

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PAPER 1

Systematic Literature Review

PSYCHOSOCIAL INTERVENTIONS FOR CAREGIVERS OF THOSE LIVING WITH DEMENTIA

ABSTRACT

Background: This paper provides a systematic review of recent studies reporting on the effectiveness of psychosocial interventions for family members providing care for people with dementia. It extends an earlier systematic review carried out by Selwood et al. (2007).

Method: A systematic search of PsycINFO, Medline and EMBASE from 2004 to 2014 yielded twelve papers that met the inclusion criteria. Further manual searches identified a further five papers. Each paper was critically assessed against Downs and Black (1998) quality framework for randomised control trials.

Results: The review identified five common intervention components including psychoeducation, practical advice, peer support, behaviour management techniques and psychological therapy. These were delivered in a range of formats, including face-to-face counselling, telephone interventions, fixed content and content that was tailored to the needs of the individual caregiver. All but two of the studies found significant improvements in the psychological wellbeing of the carer. Other outcomes included an increase in the length of time prior to nursing home placement (3 papers), an impact on the caregivers' response to behaviours that challenge (4) and an improvement in the wellbeing of the person with dementia (2). Variables that moderated the impact of the intervention on outcome included social support, severity of the dementia and ethnicity. The quality of the studies varied considerably.

Conclusions: Psychosocial interventions for caregivers of people with dementia can be beneficial. However, as the studies involved multicomponent psychosocial interventions, it is unclear which components are effective. Interventions need to be more grounded in theory. Other moderating variables need to be investigated, such as the quality of the relationship between the caregiver and the person with dementia.

INTRODUCTION

Rationale

Caring for someone with dementia can have a negative impact on the well-being of the carer and on the quality of the relationship with the person with dementia. A meta-analysis by Vitaliano, Zhang, and Scanlan (2003) indicated that caregiving is chronically stressful and can have negative and adverse effects on the caregivers' psychological, emotional and physical well-being. The prevalence rates of depression and a feeling of burden amongst spousal caregivers of older adults significantly increase (Murray, 1995). In a study by Murray & Livingston (1998) they suggested that spousal carers are at a higher risk of developing depression than age-related peers who do not perform a caring role. Furthermore, in a recent review Ablitt et al. (2009) highlighted that dementia can have a negative impact upon the quality of the relationship in a number of areas, including reciprocation of care and concern, gratification and satisfaction in the relationship (Carruth, 1996), shared pleasurable activities, reciprocity (Gallagher-Thompson et al., 2001) and overall marital quality (Wright, 1991).

These negative impacts on the carer's well-being and on the relationship can, in turn, have negative consequences for the person with dementia, depending upon how the carer manages the demands presented by their caring role. It has been highlighted by Walters et al. (2010) that those who perceive their relationship as discontinuous or changed since the onset of Dementia, are more likely to use depersonalising or objectifying terms when referring to the person with dementia they are providing care for, and to be controlling and restrictive in their approach to care. Furthermore, it has been found that the care provided may not be well tailored to the individual when there is discontinuity (Chesla et al., 1994). Conversely, a good relationship may have benefits for the person with dementia, and can lead to more empathic care (Walters et al., 2010). In a study by Burgener and Twigg (2002) they found

that the quality of the relationship was associated with better psychological well-being of the person with dementia. In addition to this, it has been found that by improving the psychological well-being of the caregiver, this can in turn have a significant impact on the severity and frequency of dementia-related symptoms such as agitation, aggression, delusions and hallucinations (Chien & Lee, 2011). The authors concluded that by improving the quality of life of the caregiver and reducing their experience of burden, caregivers are able to provide better care for those with dementia, which subsequently impacts upon the severity of the symptoms.

However, if the caregiver is able to manage and cope with the demands and challenges of dementia, this in turn is likely to have a positive effect on the care provided for the person with dementia. In a systematic review of psychosocial interventions for caregivers of people with dementia (Selwood, Johnston, Katona, Lyketsos & Livingston, 2007), it was found that brief interventions of behavioural management were successful in reducing caregiver symptoms of depression and burden. It also identified that these effects were sustained for up to 32 months. A study by Graff et al. (2007) looked at the effectiveness of a carer-focussed intervention programme on the person with dementia. They found that by training caregivers through a cognitive and behavioural psychosocial intervention aimed at increasing the meaningful activities for the person with dementia, this significantly improved the quality of life and mood not only for the person with dementia, but also their caregiver.

Given this evidence, interventions focused on the carer and on their relationship with the person with dementia are an important area for development. They may help to reduce the negative impact of caring on the well-being of the carer and improve the quality of the relationship. These are valuable outcomes in themselves, but they may also improve outcomes for the person with dementia.

The current review is an extension of the systematic review carried out by Selwood et al. (2007). The primary aim of this earlier paper was to review the short and long term efficacy of psychological interventions on the psychological well-being of caregivers of people with dementia. The authors rated the quality of each intervention study and then categorised them into groups based on their components, for example 'educational' or 'individual coping strategies'. Although the quality of the studies varied, they concluded that 'individual behavioural management techniques' interventions, which involved the application of behavioural management techniques to specific behaviours that challenge, were significantly more effective than any other intervention in alleviating caregiver depression and burden both in the short and long term. Furthermore, they found that interventions that were aimed at enhancing 'individual coping strategies', as well as those that focussed on enhancing 'coping strategies in a group setting' were also significantly effective. However, 'group behavioural management techniques' interventions which involved group sessions where caregivers discussed how to apply behavioural management techniques to behaviours that challenge, 'supportive/group therapy', which involved peer support, and 'psychoeducation' as a stand-alone intervention, which involved sharing factual information about dementia, were significantly less effective.

The current review aimed to provide an extension of the systematic review carried out by Selwood et al. (2007). Similarly to this earlier review, the primary aim of the current review was to systematically identify intervention studies for caregivers of people with dementia, rate the quality of the studies, categorise the components of the interventions and review the effectiveness of the interventions. In contrast to the earlier review, the current review focused on additional outcomes (i.e. not just the impact on caregiver's psychological well-being), including the effectiveness of the interventions on the psychological wellbeing of the person with dementia, on the length of time between diagnosis and admission to a

nursing care home, and the impact on the caregivers' response to behaviours that challenge. Furthermore, unlike the previous review, the current review also discusses the modality of the interventions and any important moderating variables. Finally, whereas Selwood et al. reviewed only single component interventions, the present review aimed to review both single and multi-component interventions.

METHOD

For the purposes of the review, psychosocial interventions are defined as non-medical interventions that are psychologically, socially or behaviourally oriented. As the most recent review on psychosocial interventions for family caregivers of people living with Dementia dealt with studies published up until 2004 (Selwood, Johnston, Katona, Lyketsos & Livingston, 2007), the present review focuses on research published after 2004.

Search Strategy

To locate studies for the review, a computerised literature search was carried out using multiple electronic databases for studies published between 2004 – 2014. All searches were limited to peer-reviewed, English-language journals and studies focussing on the older adult population (65 years or older). Keyword searches were made of the interlinked search engine OVID and included the following databases: Medline (2004 – 2014), PsycINFO (2004 – 2014) and EMBASE (2004 – 2014).

Combinations of keywords were used in the following groupings a) Alzheimer, Dementia, Cognitive Impairment b) family, caregiver, caregiving, marriage, marital, spouse, spousal, couple or partner and c) 'family intervention', intervention, support or treatment.

Inclusion/Exclusion Criteria

Table 1.1 Inclusion and Exclusion criteria for literature

Inclusion	*Exclusion*
• *Articles must include psychosocial interventions* • *Articles must include psychosocial interventions aimed at family caregivers* • *The people receiving care from the participants in the study must have Dementia* • *Caregiving for the individual in the community* • *Articles must include a clear and comprehensive description of the components of the intervention* • *The study must evaluate the effectiveness of the intervention* • *Studies must be in English or translated into English* • *Must be peer-reviewed.* • *Articles published after 2004.*	• *Articles not focussing on the family caregiver* • *Articles that describe a study protocol, without any data collection or analysis* • *Care-recipient does not have Dementia* • *Studies that are in another language other than English* • *Literature reviews* • *Duplicated research.* • *Not peer reviewed.* • *Articles published before 2004.* • *Not caregiving for the person in the community.*

A total of 76 studies were identified by the databases. After excluding papers that were not written in English (7), were published before 2004 (37) and were not peer reviewed (8), this left a total of 24 papers. The abstracts and titles of these 24 papers were used to further exclude studies that were unrelated to Dementia (9), not based in the community setting (1) or were duplicated in the search results (2). This left a total number of 12 studies that met the inclusion criteria.

The reference lists of each of these 12 studies were then searched to identify intervention studies not captured by the database search. This was an important strategy for identifying studies, because the inclusion of family members in the psychosocial interventions was not always explicit in the title or abstract of the journal article. This search yielded an additional 10 studies. A further search was conducted to identify research papers that had cited these 22 studies using following databases: Medline (2004 – 2014), PsycINFO

(2004 – 2014) and EMBASE (2004 – 2014) as well as Google Scholar. This search yielded an additional 7 studies, totalling 29 studies.

After applying the remaining exclusion criteria (see Table 1.1), 12 studies were omitted from the review because they were either RCT design protocols without any data analysis or outcomes (6) or literature reviews (6), leaving a total of 17 studies to be included in this review.

Table 1.2. Summary of Studies

Key

I	Intervention Group
TAU	Treatment as Usual
WL	Waiting List
RCT	Randomised Control Trial
CO	Cross-Over

Study Title	*Authors*	*n =*	*Desig n*	*Type of intervention*	*Theoretical Underpinnings*	*Measures*	*Assessment intervals*	*Statistical Analysis*	*Outcome/Conclusion*
Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease	Mittleman, Haley, Clay & Roth (2006)	I = 203 TAU = 203	RCT	Multimodal Enhanced Counselling Support (6 sessions) - Individual and family sessions - Weekly support group - Ad-hoc telephone conversations - Behavioural management sessions - Promoting better conversation between family members - Crisis interventions - Practical advice on resources available and financial planning	None.	1. Global Deterioration Scale 2. Memory and Behaviour Problems Check-list 3. Geriatric Depression Scale 4. The Burden Scale 5. Stokes Social Network Questionnaire 6. OARS Physical Health Form	Baseline 4, 8, 12 months, and every 6 months after treatment until placement or death.	- Cox proportional hazards models - Mediation analysis	- Intervention group able to keep person with dementia at home for longer (I = 1,766 days vs. TAU =1,181 days) - <u>4, 8 and 12 months</u> Intervention led to: Improvements in caregivers' satisfaction with social support, response to patient behaviour problems, and symptoms of depression.
Tailored Activities to Manage Neuropsychiatric Behaviours in Persons with Dementia and to Reduce	Gitlin et al. (2008)	I = 30 WL = 30 dyads	RCT CO	Tailored Activity Program - 8 sessions (6 home visits, 2 telephone contacts) - Activity Prescriptions developed - Stress Management strategies	Environmental vulnerability /reduced-threshold model	1. Revised Memory and Behaviour Problem Checklist. 2. Cornell Scale for Depression 3. Activity engagement was measured by Likert scales designed by the study. 4. Quality of Life – AD Scale 5. Mastery Scale 6. Zarit Burden Scale	Baseline and at 4 months at treatment endpoint.	- Chi square and Wilcoxon rank tests - ANCOVA and logistic regression procedures	- <u>4 months</u> Intervention led to: - Reduction in frequency of problematic behaviours for intervention condition (but not statistically significant) - Intervention group showed overall improved quality of life.

Caregiver Burden: A Randomised Pilot Study						7. CES-D scale 8. Confidence using activities (developed by the researchers) 9. Task Management Strategy Index			- There was no significant difference in depression or burden scores.
A telephone delivered psychosocial intervention improves dementia caregiver adjustment following a nursing home placement	Davis, Tremont, Bishop, Fortinsky (2011)	I = 23 TAU = 23	RCT	Family Intervention: Telephone Tracking Nursing Home (10 telephone calls over 3 months) - Problem Solving - Psychoeducation - Counselling - Specific interventions to match problems	None.	1. Caregiver Guilt Questionnaire for Nursing Home Placement 2. Zarit Burden Interview 3. Nursing Home Hassles Scale 4. Ohio Department of Aging Family Satisfaction 5. Visitation Frequency and quantity 6. Health-Related QoL 7. Social Support 8. Negative Reactions to Care Recipient Behaviour	Baseline and 3 months at treatment end-point.	Mixed Model ANOVA	<u>3 months</u> Intervention led to: - Greater reduction in feelings of guilt No significant effect on o Anxiety o Depression o Access to community resources o Improvement in Health o Reaction to patient behaviour problems
Preserving Health of Alzheimer Caregivers: Impact of a Spouse Caregiver Intervention	Mittleman, Roth, Clay & Haley (2007)	I = 199 TAU = 197	RCT	- 2 Individual counselling tailored to individuals specific difficulties - 4 Family sessions with primary caregiver and one other family member - Encouraged to participate in support groups - Ad-hoc telephone contacts	None.	1. Self-Rated Health 2. Subjective health related questions 3. Geriatric Depression Scale 4. Social Network Questionnaire	Baseline, 4, 8, 12, 18 and 24 months after treatment.	Mixed modal growth curve analysis	<u>4, 8, 12, 18 and 24 months</u> - Intervention led to: o Significant benefits in caregiver self-reported health o Health outcomes mediated by perceived social support.
Effective psychosocial intervention for family caregivers	Andrén & Elmståhl (2008a)	I = 153 TAU = 155	RCT	Group Intervention - 8 caregivers in each group - 5 2 hour sessions - Telephone support offered (1 x	None.	1. Katz Index of ADL 2. Berger Scale 3. MMSE 4. The Caregiver Burden Scale	Baseline, 6, 12, 18, 24, 30, 36, 42, and 48 months after	- Multiple Linear Regression Analysis - Independent sample t-tests - Cox's Regressions Analysis - Odd's Ratio	<u>6, 12, 18, 24, 30, 36, 42, and 48 months</u> Intervention led to: - Longer time caring for their loved one at home.

lengthens time elapsed before nursing home placement of individuals with Dementia				weekly by physician, daily by nurse and 1 x weekly by counsellor). - Psychoeducation - Information on resources - Provision of a support group following formal intervention (90 minutes, fortnightly)		5. Nottingham Health Profile	treatment.		
An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with Dementia in mainland China	Wang, Chien & Lee (2012)	I = 39 TAU = 39	RCT	Support Group - 12 sessions (90 minutes) - Psychoeducation - Peer Support - Problem Solving - Psychological support	None.	1. Neuropsychiatric Inventory Caregiver Scale 2. Family Support Service Index 3. QoL	Baseline, 1 and 24 months after treatment.	- Two way ANOVA - Mann-Whitney U	<u>1 and 24 months</u> Intervention led to: - Significant improvements in QoL compared to controls. - Caregivers more confident at managing the care recipient's problematic behaviours.
Does a family meetings intervention prevent Depression and Anxiety in a family of Dementia patients? A randomised Trial	Joling et al. (2012)	I = 96 TAU = 96 dyads	RCT	Six counselling sessions (with other family members) - Psychoeducation - Problem Solving Techniques - Enhance social networks - Improve emotional and instrumental support - Ad-hoc counselling available between sessions.	None.	1. Centre for Epidemiologic Studies Depression Scale (CES-D) 2. Hospital Anxiety and Depression Scale (HADS) 3. Caregiver Reaction Assessment 4. Health Related QoL	Baseline, 3 and 6 months after treatment.	- Unadjusted Poissin Regression Analysis - Multi-level modelling	<u>3 and 6 months</u> Intervention group: - Did not significantly reduce anxiety/depression - No significant intervention effects found on burden

Randomised control trial of a Dementia care programme for families of home resided people with Dementia	Chien & Lee (2011)	I = 46 TAU = 46	RCT	Comprehensive Dementia Care Family Program (10, 2 hour sessions bi-weekly) - Psychoeducation - Peer Support - Interdisciplinary CMHT component - Problem Solving - Psychological Support	None.	1. Family Caregiver Burden Inventory (FCBI) 2. WHO Quality of Life Measure 3. Six-Item social Support Questionnaire 4. Family Support Services Index 5. Neuropsychiatric Inventory Questionnaire	Baseline and 18 months after treatment.	Repeated measures MANOVA	<u>18 months</u> Intervention led to: - Significant improvement in caregiver burden, quality of life, dementia client's symptom severity, frequency and length of time before institutionalisation.
Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 month	Andrén & Elmståhl (2008b)	I = 153 TAU = 155	RCT	Group intervention (5, 2 hour sessions) - Psychoeducation - Problem-solving - Peer support - After formal intervention, participants could continue a 'conversation group' for 3 months following, meeting for 90 minutes every week to share experiences and support.	None.	1. The Caregiver Burden Scale 2. The Carers' Assessment of Satisfaction Index 3. Nottingham Health Profile scale 4. Katz Index of ADL	Baseline, 6 & 12 months after treatment.	Independent sample t-tests	<u>6 and 12 months</u> Intervention led to: - Significant effect caregiver burden for those patients with low severity of dementia, but no significant effect for those with higher severity of dementia.
Family caregivers' assessment of symptoms in persons with dementia using the gBs- scale: differences in	Dahlrup, Andrén & Elmståhl (2011)	I = 129 TAU = 133	RCT	Group intervention - 8 caregivers per group - 5 week, 2 hour sessions - Psychoeducation - Peer support - Offered to continue conversational groups under supervision of the	None.	1. Mini-Mental state examination (MMse) 2. The gottfries-Bråne-steen scale (gBs-scale) 3. The Berger scale 4. The Katz index of ADL	Baseline, 6, 12 & 18 months after treatment.	Two-tailed independent-sample t-tests.	<u>6, 12 and 18 months</u> Intervention led to: - Better understanding about the disease and its symptoms. Family caregivers in the intervention group were more aware of the different behaviours occurring and, further, that these behaviours could be

rating after psychosocial intervention – an 18-month follow-up study				counsellor (over half agreed to this)					caused by the dementia disorder.
A 3 Country Randomized Controlled Trial of a Psychosocial Intervention for Caregivers Combined with Pharmacological Treatment for Patients with Alzheimer's Disease: Effects on Caregiver Depression	Mittleman, Brodaty, Wallen & Burns (2008)	I = 79 TAU = 79	RCT	Counselling sessions (5, 2 hour sessions) - Included additional family members. - Ad hoc counselling on demand by telephone was available to spouse caregivers and their family members for the duration of study participation. - Content depended on the needs of each caregiving family. - Psychoeducation. - Information about available resources in the community. - Help in understanding how to manage difficult patient behaviour.	None.	1. Beck Depression Inventory 2. The Stokes Social Network List 3. Global Deterioration Scale 4. Alzheimer's Disease Assessment Scale 5. Cooperative Study- Activities of Daily Living Inventory 6. Revised Memory and Behaviour Problems Checklist	Baseline, 3, 6, 9, 12, 18, 24 months after treatment.	- Linear regression analyses - Multilevel growth curve analyses	<u>3, 6, 9, 12, 18 and 24 months</u> Intervention led to: - Reduced depression scores in spouses of persons with Alzheimer's disease taking donepezil.
Telephone-delivered psychosocial intervention reduces burden in dementia caregivers	Tremont, Davis, Bishop & Fortinsky (2008)	I = 23 TAU = 23	RCT	Telephone Intervention (6 weekly calls, 12 additional contacts fortnightly) - Psychoeducation - Identification of specific problems - Behavioural management	- Psychosocial transitions (Tyhurst, 1958) - Transactional stress and coping (Lazarus & Folkman, 1984). - McMaster Model	1. Burden Interview 2. Revised Memory & Behaviour Problem Checklist 3. Geriatric Depression Scale 4. Alzheimer's Disease Knowledge Test 5. SF36 General Health 6. Self-Efficacy Scale 7. Family Assessment Device	Baseline and 12 months after treatment.	Mixed model ANOVA	<u>12 months</u> Intervention led to: - Significantly reduced burden. - Less severe reactions to memory and behavioural problems. - Although not significant, there was a trend towards less depressive

				- Psychological interventions at therapist discretion - Focus on social support	of Family Functioning, Epstein, Bishop & Levin, 1978).	8. Multidimensional Sale of Perceived Social Support			symptoms reported.
Enhancing Caregiver Health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention	Elliott, Burgio, & DeCoster (2010)	I = 238 TAU = 257	RCT	Research for Enhancing Alzheimer's Caregiver Health (REACH) II trial - 12 sessions over 6 months (9 f2f, 3 telephone contacts) - 5 telephone support groups - Intervention as Belle et al., (2006).	None.	1. Items addressing CGs' physical health were four items from REACH II measures 2. Zarit Subjective Burden Interview 3. Frustrations of Caregiving from the REACH-II subscale 4. Caregiver Assessment of Functional Dependence and Caregiver Upset 5. Revised Memory and Behaviour Problem Checklist 6. Centre for Epidemiologic Studies Depression Scale	Baseline and 6 months at treatment end-point.	ANOVA	<u>6 months.</u> Intervention led to: - Better self-rated health and subsequent reductions in caregiver burden. - This relationship was mediated through decreases in caregiver depression levels. - The finding that this intervention improved caregiver health in four domains of health (general self-rated health, sleep, mood improvement, and physical improvement).
Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups	Belle et al. (2006)	Hispanic /Latino I = 82 TAU = 86 White/ Caucasian I = 96	RCT	Telephone support groups - 12 sessions over 6 months (9 f2f, 3 telephone contacts) - 5 telephone support groups - Identified 5 target areas to reduce risk and designed a tailored intervention - Behaviour Management - Psychoeducation - Problem solving - Didactic instruction - Skills Training - Role Playing - Stress Management Techniques	None.	1. Centre for Epidemiologic Studies Depression Scale 2. Zarit Burden Interview 3. Self-Care 4. Social Support 5. Revised Memory and Behaviour Problem Checklist	Baseline and 6 months at treatment end-point.	Generalized estimating equation (GEE) models with robust (sandwich) SEs performed global tests.	<u>6 months.</u> Intervention led to: - Statistically significantly greater improvements in quality of life for white or Caucasian and Hispanic or Latino caregivers but not for black or African-American - White/Caucasian reported higher levels of social support following the intervention. - Hispanic/Latino caregivers reported improvements in depressive symptoms. - Statistically significant reductions in

		TAU = 86 Black / African American I = 83 TAU = 85		- Social Support - Cognitive Reframing					symptoms of depression.
Helping Carers to Care – The 10/66 Dementia Research Group's randomised control trial of a caregiver intervention in Russia	Gavrilova et al. (2009)	I = 30 TAU = 30	RCT	10/66 Dementia Research Group brief caregiver intervention - Manualised modules over 5 weekly 30 minute sessions - Psychoeducation - Training on managing problematic behaviours	None.	1. Zarit Burden Interview 2. Self-Reporting Questionnaire 3. WHOQOL-BREF 4. Neuropsychiatric Inventory 5. DEMQOL	Baseline and 6 months after treatment.	Primary end-point analysis	<u>6 months.</u> Intervention led to: - Significant reductions in caregiver burden and increases in carer quality of life - No significant differences were found for the quality of life for the person with dementia.
Effects of Community Occupational Therapy on Quality of Life: Mood and Health Status in	Graff et al. (2007)	I = 68 TAU = 67	RCT	Occupational Therapy intervention - 10, 1 hour sessions over the course of 5 weeks - Identify meaningful activities the participants wanted to improve - OT's developed plans to improve performance of daily activities	None.	1. Dementia Quality of Life Instrument 2. General Health Questionnaire 3. Cornell Scale for Depression 4. Centre for Epidemiologic Depression Scale 5. Mastery Scale 6. Cumulative Illness Rating Scale for Geriatrics 7. GDS	Baseline, 6 and 12 weeks at treatment end-point.	ANCOVA	<u>6 and 12 weeks.</u> Intervention led to: - Significantly better quality of life for both caregivers and the person with dementia. - Caregivers and people living with dementia reported significantly better mastery over life.

Dementia Patients and Their Caregivers: A Randomised Control Trial				- Caregivers trained through cognitive and behavioural interventions - Problem solving - Coping strategies		8. MMSE 9. Revised Memory and Behavioural Problems Checklist			- Caregivers and people living with dementia reported significantly improved mood.
Training Community Consultants to Help Family Members Improves Dementia Care: A Randomised Control Trial	Teri, McCurry, Logsdon & Gibbons (2005)	I = 47 TAU = 48	RCT	Seattle Protocol - 8 weekly sessions, and 4 monthly phone calls - Problem-solving using behavioural approach - Improving caregiver communication - Increasing pleasant events - Developing strategies to improve caregiver mood and enhance support - Consultants had freedom to use clinical judgement and modify to tailor to individual needs	Social Learning Theory	1. Treatment Integrity – Consultants completed a checklist to check adherence to protocol, caregiver compliance with homework and training recommendations, consultants rated whether caregivers had completed their assigned homework during the previous week. Clinical supervisors coded audiotaped sessions using a Therapist Adherence Checklist form. 2. Target Problems – Consultants used three questions to identify behavioural problems of concern, and monitored their frequency. 3. Center for Epidemiologic Studies Depression Scale (CES-D) 4. Hamilton Depression Rating Scale 5. Caregiver Sleep Questionnaire 6. Perceived Stress Scale 7. Screen for Caregiver Burden 8. Short Sense of Competence Questionnaire 9. The Neuropsychiatric Inventory Revised Memory and Behaviour Problem Checklist 10. The Quality of Life in Alzheimer's Disease	Baseline, 2 and 6 months after treatment.	- Cox proportional hazards survival analyses - Paired t-tests	<u>2 and 6 months</u> Intervention led to: - A significant reduction in self-reported depression, subjective burden, reactivity to problematic behaviours and increase in quality of life for the person with dementia.

QUALITY REVIEW

In order to determine the quality of the reviewed studies, several critical appraisal frameworks were examined, such as Jadad et al. (1989), which ascertains how well randomised control trials reduce bias. However, it was felt that the comprehensive checklist developed by Downs and Black (1998), which comprises of several domains, including criteria to assess the extent to which studies reduce bias, served as a useful tool in evaluating the quality of the evidence in this review.

All of the studies presented in this review were randomised control trials, and the Downs and Black checklist has been shown to have good application in assessing the quality of these designs (Downs & Black, 1998). The checklist assesses the methodological strengths and weakness; rates the quality of reporting, appraises the internal validity of each study, for example determining the degree the study design, conduct and statistical analysis minimise errors or biases; contains items to assess external validity and determines whether each study meets power. The Downs and Black checklist has also been shown to have good inter-rater reliability.

A template checklist was established based upon this (see Appendix A) and each of the studies was scrutinised against these criteria (see Table 1.3). The criteria reviewed by this checklist assess the *quality of reporting*, *internal validity*, *internal validity – confounding variables*, *power* and unlike other checklists it includes items to assess *external validity* (see below).

- Reporting –assesses whether there is sufficient information provided in the paper to enable the reader to develop an unbiased conclusion of the findings of the study.
- External Validity –assesses the extent to which the findings could be generalised to the population.

- Internal Validity –Assesses the degree of bias in the measurement of the intervention and the outcome.
- Internal Validity (Confounding – Selection Bias) –Assesses the studies attempts to account for confounding variables in the recruitment and selection of participants.
- Power – This enables the reader to determine whether results and effect size could be due to chance (Downs & Black, 1998).

Table 1.3. Quality Criteria against Black & Downs (1998) Checklist

Key

	Item 5
0 = No/Unable to determine 1 = Yes	0 = No/Unable to determine 1 = Partially 2 = Yes

Quality Criteria		Journal Article																
		Mittleman, Haley, Clay & Roth (2006)	*Gitlin* et al. *(2008)*	*Davis, Tremont, Bishop, Fortinsky (2011)*	*Mittleman, Roth, Clay & Haley (2007)*	*Andrén & Elmståhl (2008a)*	*Wang, Chien & Lee (2012)*	*Joling* et al. *(2012)*	*Chien & Lee (2011)*	*Andrén & Elmståhl (2008b)*	*Dahlrup, Andrén & Elmståhl (2011)*	*Mittleman, Brodaty, Wallen & Burns (2008)*	*Tremont, Davis, Bishop & Fortinsky (2008)*	*Elliott, Burgio, & DeCoster (2010)*	*Belle* et al. *(2006)*	*Gavrilova* et al. *(2009)*	*Graff* et al. *(2007)*	*Teri, McCurry, Logsdon & Gibbons (2005)*
Reporting																		
1	***Is the hypothesis/aim/objective of the study clearly described?***	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2	***Are the main outcomes to be measured clearly described in the Introduction or Methods section?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
3	***Are the characteristics of the patients included in the study clearly described?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
4	***Are the interventions of interest clearly described?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
5	***Are the distributions of principal confounders in each group of subjects to be compared clearly described?***	0	0	0	0	0	0	0	0	0	0	0	2	1	1	2	0	0
6	***Are the main findings of the***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1

Quality Criteria		Journal Article																
		Mittleman, Haley, Clay & Roth (2006)	*Gitlin* et al. *(2008)*	*Davis, Tremont, Bishop, Fortinsky (2011)*	*Mittleman, Roth, Clay & Haley (2007)*	*Andrén & Elmståhl (2008a)*	*Wang, Chien & Lee (2012)*	*Joling* et al. *(2012)*	*Chien & Lee (2011)*	*Andrén & Elmståhl (2008b)*	*Dahlrup, Andrén & Elmståhl (2011)*	*Mittleman, Brodaty, Wallen & Burns (2008)*	*Tremont, Davis, Bishop & Fortinsky (2008)*	*Elliott, Burgio, & DeCoster (2010)*	*Belle* et al. *(2006)*	*Gavrilova* et al. *(2009)*	*Graff* et al. *(2007)*	*Teri, McCurry, Logsdon & Gibbons (2005)*
	study clearly described?																	
7	***Does the study provide estimates of the random variability in the data for the main outcomes?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
8	***Have all important adverse events that may be a consequence of the intervention been reported?***	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	1
9	***Have the characteristics of patients lost to follow-up been described?***	0	1	0	0	1	1	1	1	1	1	1	0	0	1	1	1	0
10	***Have actual probability values been report-ed(e.g.0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
External validity																		
11	***Were the subjects asked to participate in the study representative of the entire population from which they were recruited?***	0	0	0	0	0	0	0	0	1	1	0	0	0	1	0	0	0
12	***Were those subjects who were prepared to participate representative of the entire population from which they were recruited?***	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Quality Criteria		Journal Article																
		Mittleman, Haley, Clay & Roth (2006)	*Gitlin* et al. *(2008)*	*Davis, Tremont, Bishop, Fortinsky (2011)*	*Mittleman, Roth, Clay & Haley (2007)*	*Andrén & Elmståhl (2008a)*	*Wang, Chien & Lee (2012)*	*Jolinq* et al. *(2012)*	*Chien & Lee (2011)*	*Andrén & Elmståhl (2008b)*	*Dahlrup, Andrén & Elmståhl (2011)*	*Mittleman, Brodaty, Wallen & Burns (2008)*	*Tremont, Davis, Bishop & Fortinsky (2008)*	*Elliott, Burgio, & DeCoster (2010)*	*Belle* et al. *(2006)*	*Gavrilova* et al. *(2009)*	*Graff* et al. *(2007)*	*Teri, McCurry, Logsdon & Gibbons (2005)*
13	***Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?***	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1
		Internal Validity																
14	***Was an attempt made to blind study subjects to the intervention they have received?***	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0
15	***Was an attempt made to blind those measuring the main outcomes of the intervention?***	0	0	1	0	0	1	1	1	0	0	1	1	0	0	1	1	0
16	***If any of the results of the study were based on "data dredging", was this made clear?***	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1
17	***In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cas1es and controls?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
18	***Were the statistical tests used to assess the main outcomes appropriate?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1

Quality Criteria		Journal Article																
		Mittleman, Haley, Clay & Roth (2006)	*Gitlin* et al. *(2008)*	*Davis, Tremont, Bishop, Fortinsky (2011)*	*Mittleman, Roth, Clay & Haley (2007)*	*Andrén & Elmståhl (2008a)*	*Wang, Chien & Lee (2012)*	*Joling* et al. *(2012)*	*Chien & Lee (2011)*	*Andrén & Elmståhl (2008b)*	*Dahlrup, Andrén & Elmståhl (2011)*	*Mittleman, Brodaty, Wallen & Burns (2008)*	*Tremont, Davis, Bishop & Fortinsky (2008)*	*Elliott, Burgio, & DeCoster (2010)*	*Belle* et al. *(2006)*	*Gavrilova* et al. *(2009)*	*Graff* et al. *(2007)*	*Teri, McCurry, Logsdon & Gibbons (2005)*
19	***Was compliance with the intervention/s reliable?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
20	***Were the main outcome measures used accurate?***	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Internal validity - confounding (selection bias)																		
21	***Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?***	1	0	0	0	1	1	0	1	0	0	1	1	1	1	1	1	1
22	***Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?***	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1
23	***Were study subjects randomised to intervention groups?***	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	1
24	***Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?***	0	1	1	1	0	0	1	0	0	0	1	1	1	1	1	1	1
25	***Was there adequate adjustment for confounding***	1	1	1	0	0	1	1	1	0	1	1	1	0	0	0	0	0

Quality Criteria		Journal Article																
		Mittleman, Haley, Clay & Roth (2006)	*Gitlin* et al. *(2008)*	*Davis, Tremont, Bishop, Fortinsky (2011)*	*Mittleman, Roth, Clay & Haley (2007)*	*Andrén & Elmståhl (2008a)*	*Wang, Chien & Lee (2012)*	*Joling* et al. *(2012)*	*Chien & Lee (2011)*	*Andrén & Elmståhl (2008b)*	*Dahlrup, Andrén & Elmståhl (2011)*	*Mittleman, Brodaty, Wallen & Burns (2008)*	*Tremont, Davis, Bishop & Fortinsky (2008)*	*Elliott, Burgio, & DeCoster (2010)*	*Belle* et al. *(2006)*	*Gavrilova* et al. *(2009)*	*Graff* et al. *(2007)*	*Teri, McCurry, Logsdon & Gibbons (2005)*
	in the analyses from which the main findings were drawn?																	
26	***Were losses of patients to follow-up taken into account?***	1	1	0	0	1	1	1	1	0	0	1	1	0	1	1	1	1
Power																		
27a	***Did the paper report a power analysis?***	0	0	0	0	0	1	1	1	0	0	1	0	0	0	1	0	0
27b	***Was the sample size to achieve power achieved?***	0	0	0	0	0	1 Large	1 Medium	1 Large	0	0	1 Medium	0	0	0	1 Large	0	0
27c	***If no power analysis indicated, did the study meet the cut-off for detecting a medium or large effect?***	1 Medium	1 Large	0	1 Medium	1 Medium	NA	NA	NA	1 Medium	1 Medium	NA	0	1 Medium	1 Medium	NA	1 Medium	1 Large
	Quality Profile Score																	
	Total	18	19	16	15	18	21	22	21	17	18	24	20	18	22	24	20	19

Quality of Studies according to Downs & Black (1998) Checklist

The checklist enables a quality profile to be developed for each study to determine whether they are of a poor or good quality. Of the 17 studies presented here, none met every criteria set out by the checklist, and varied in terms of their overall quality.

Reporting

The checklist assessed the quality of reporting against 10 items (see Table 1.3). Studies could obtain a maximum score of 11 for the quality of the reporting. Two of the studies scored ten, two scored nine, ten scored eight, two scored seven and one scored six.

All of the studies bar Mittleman, Haley, Clay and Roth (2006) clearly described their hypothesis, aims and objectives. All of the main outcomes were clearly stated in the introduction and methods section. All of the studies included a clear description of the characteristics of the participants recruited into the study; the degree of detail varied. Furthermore, all of the interventions were clearly described, but again they differed in terms of the amount of detail provided. All of the main findings were clearly stated for each of the studies, as well as random estimates of variability in the data for the main outcomes. All of the studies reported actual probability values for the main outcomes except where the value was less than 0.001.

The majority of the studies failed to report how the principal confounders were distributed in each group of subjects to be compared, except for Tremont, Davis, Bishop and Fortinsky (2008) and Gavrilova et al. (2009) who clearly stated what the principal confounders were, and how each group compared on these confounders. Elliot, Durgio and De Coster (2010) and Belle at al. (2006) partially accounted for confounding variables, but this was not as clear as in the former studies. In addition to this, only three of the studies reported any adverse effects (Mittleman, Brodaty, Wallen & Burns, 2008; Belle et al. 2006 and Teri, McCurry, Logsdon & Gibbons, 2005). Only 11 out of 17 reported on characteristics of participants lost to follow-up. Whilst there was some variability in the quality of reporting on the characteristics of the participants lost to follow-up, and consistent poor quality or

reporting of possible confounding variables and important adverse effects, overall the quality of reporting within this sample of studies was good.

External validity

The checklist assessed the quality of external validity against three items (see Table 1.3). The external validity criteria assess the extent to which the findings could be generalised to the population. It must be noted, however, that a score of 0 in any of these domains either reflects that the study did not meet the criteria or it was unable to be determined. In other words, in some cases the sample or setting may have been representative of the population, but insufficient information was provided about whether this was the case or not.

The first criteria related to whether the subjects who were asked to participate in the study were representative of the entire population from which they were recruited. In order to achieve a score of 1 for this item, participants would either have to comprise of the entire source population, be an unselected sample of consecutive patients, or a random sample. In order for true random sampling to occur, a list of all the relevant population needs to exist. If the study does not report the proportion of the source population from which the patients are derived, the question is answered as unable to determine (Downs & Black, 1998). Of the 17 studies, two obtained a score of one (Andrén & Elmståhl, 2008b; and Dahlrup, Andrén & Elmståhl, 201l) as they provided details of the entire source population the sample derived from. For the remaining studies, the recruitment was through either volunteer sampling, or opportunistic sampling and it is difficult to know how representative the samples were of the source population.

The second criterion to assess the quality of external validity was to determine whether the sample was representative of the entire population that they were recruited from. In order to achieve this, studies would need to demonstrate that the distribution of the main confounding factors were the same in the study sample, as they were in the general population (Downs & Black, 1998). All of the studies failed to meet this criterion.

The final criterion assessed whether, in terms of staff, places and facilities, the intervention was representative of that in use by the source population (Downs & Black, 1998). All of the studies described in this review, with the exception of two, used the facilities that the source population would access. The two studies where this was not the case, involved telephone interventions that were delivered by interventionists trained for this purpose (Davis, Tremont, Bishop & Fortinsky, 2011; Tremont, Davis, Bishop & Fortinsky, 2008). All of the studies were of a poor quality in regards to external validity, and thus generalisation is difficult.

Internal Validity – Bias

The checklist assessed the quality of internal validity – bias against seven items. This domain evaluated the degree of bias in the measurement of the intervention and the outcome (Downs & Black, 1998).

Overall, the papers had an average internal validity scoring between four and six out of a possible eight. The initial criteria of this domain are concerned with controlling experimenter bias by blinding the participant, the experimenter or both. Only one study (Belle et al. 2006) was designed as a double-blind experiment, nine were single-blind designs, whilst seven studies made no reference to blinding (see Table 1.3, Items 14 and 15). In the study by Belle et al. (2006) they ensured that neither the participant nor the person assessing the outcome measures was aware of the condition the individual was allocated to. According to Jadad et al. (1998), double-blind studies are the most effective at reducing bias. If the experimenter is not blinded to the condition of the participant, they are subjected to experimenter bias. This occurs as the experimenter may have a preconceived expectation as to the outcome of the experimental group, and therefore may overinflate the results leading to a Type I error. Similarly, if the participant is not blinded from the condition they have been allocated they may have expectations of the outcome and this may subsequently affect their psychological responses. With the exception of Belle et al. (2006), all of those providing the intervention were aware that they were providing the treatment condition. Of the nine studies that

were single-blind, two of the studies had blinded the participants and the remaining seven studies had attempted to blind the assessor of the outcome measures.

Of the remaining seven studies that did not report whether any blinding had occurred, these studies are at substantial risk of bias and the Hawthorne Effect, in which the beliefs of the experimenter or the participants can substantially influence the outcomes of the study. Thus the findings of these studies, and the strength of the significance, should be viewed with caution.

However, all of the studies showed good internal validity in the measurement of the intervention and outcome (see Table 1.3). Whilst the blinding was poor, the studies obtained an average score for their quality of internal validity in this area.

Internal Validity - Confounding (selection bias)

The checklist assessed the quality of internal validity against six items. This domain determines the extent to which each study attempts to account for confounding variables and within the selection process (Downs & Black, 1998).

The studies in this review differed substantially in their internal validity scores and showed variability in their ability to reduce selection bias. A maximum score of six was possible in this domain. The study by Andrén and Elmståhl (2008b) scored one, indicating very poor internal validity. Other studies that showed poor internal validity were those of Mittleman, Roth, Clay and Haley (2007) and Dahlrup, Andrén & Elmståhl, (2011) obtaining a score of two; and Andrén & Elmståhl, (2008a) obtaining a score of three.

Internal validity is the degree to which we can conclude that the intervention caused the changes in the response variable. Given the failure of these studies to adequately control for confounding variables and selection bias, any treatment effect attributed to the intervention must be viewed with caution. It is plausible that the treatment effect in these studies may be attributed to other variables that this study has not accounted for, and therefore reduces the credibility for a cause-and-effect relationship, should a significant effect exist.

The remaining studies showed good internal validity scoring six (Mittleman, Brodaty, Wallen and Burns, 2008; Tremont, Davis, Bishop & Fortinsky, 2008), five (Mittleman, Haley, Clay & Roth, 2006; Gitlin et al. 2008; Wang, Chien & Lee, 2012; Joling et al. 2012; Chien & Lee, 2011; Belle et al. 2006; Gavrilova et al., 2009; Graff et al. 2007; Teri, McCurry, Logsdon & Gibbons, 2005) and four against the checklist (Davis, Tremont, Bishop, Fortinsky, 2011; Elliott, Burgio, & De Coster, 2010). Some of these studies included confounding variables in the analysis, such as gender, ethnicity, age, the amount of time spent caregiving and the severity of the dementia to determine whether these variables accounted for any of the effects observed. Once these effects were accounted for, any other variance could be attributed more convincingly to the treatment effect. Although it is impossible to account for every variable that may influence outcomes, as these studies controlled for known confounding variables and attempted to reduce selection bias, a cause-and-effect relationship is deemed to have more merit.

The majority of studies, with the exception of three, did randomise participants' appropriately, reducing the likelihood of selection bias (see item 23, Table 1.3) and reducing additional threats to internal validity. In the three studies where the sample was not randomised, but selected based upon their geographical location (Andrén & Elmståhl, 2008a; Chien & Lee, 2011; Andrén & Elmståhl, 2008b; Dahlrup, Andrén & Elmståhl, 2011), these studies are at risk of drawing conclusions that may not be accurate. There may be substantial differences between the geographical locations of the control and experimental group, for example sociodemographic factors. Any substantial difference between groups prior to the treatment may have a significant influence on the outcome and distort the results.

Power

As some of the papers did not report a power value, the criterion provided by Downs and Black (1998) was adapted (see Table 1.3, item 27) to determine a) whether the paper reported a power analysis or not, b) whether the sample size was achieved. For those studies that did not report a power

analysis, a general rule was followed to determine if the sample size was large enough to determine an effect. The test carried out by the studies that requires the smallest sample size to achieve adequate power is an independent samples t-test. According to G*Power, with alpha set at .05, and power at 0.8, each group would need to have at least 64 participants in each group to detect a medium effect (d = 0.5) or at least 26 in each group to detect a large effect (d = 0.8). Therefore the final criterion in this domain was, for those studies that did not report a power analysis c) whether the study met the cut-off for detecting a medium-sized effect or large effect (see Table 1.3).

After applying these rules each of the studies, with two exceptions, had a sufficient sample size in each condition to detect large to medium effects. By having sufficient power, this reduces the likelihood of type II errors being made, in which the null hypothesis is not rejected when it should have been. The two studies that did not achieve statistical power were those that used a telephone intervention (Davis, Tremont, Bishop & Fortinsky, 2011; Tremont, Davis, Bishop & Fortinsky, 2008) as the sample was too small. Therefore the findings from these studies may have involved type II errors.

Overall Quality

Each of the studies varied in terms of their overall quality. As the final domain was adapted studies can obtain a maximum quality profile score of 29 as opposed to the original 30 (see Table 1.3). None of the studies achieved this, and each of them has demonstrated strengths and weaknesses in each of the domains as discussed above. However, some of the studies met a larger proportion of overall quality criteria than others. For example, Gavrilova et al. (2009) obtained a total quality profile score of 24 compared to that of Mittleman, Roth, Clay and Haley (2007) who obtained a quality profile score of 15.

RESULTS

The findings from the reviewed papers are discussed below in relation to: the intervention components, the modality of treatment delivery and the outcomes on which the interventions had an

impact. Whilst no study was judged to merit exclusion from the review according to the Downs and Black (1999) framework, the findings discussed should be viewed with caution, especially in relation to the generalisability of the findings to the general population due to poor external validity. The lack of controls for threats to internal validity also increases the risk of bias, which could results in both type I and type II errors. Thus, it is difficult to ascertain whether any significant effects are due to the intervention itself, or due to confounding variables that have not been controlled for, such as the severity of the dementia, or due to lack of blinding leading to experimenter bias or the Hawthorne effect. Therefore, the findings of the studies in this review should still be viewed with caution.

Intervention components

As each of the studies involved multi-component intervention packages, the focus of this section of the review was to describe what the individual components were.

Psychoeducation

Psychoeducation appeared to be the most frequently included component of interventions offered. Twelve of the interventions described included an educational component, in which they covered a broad range of topics including; information about the different types of dementia, the symptoms of dementia, the prognosis of the disease, typical behavioural changes to expect, education material on self-care, the psychological impact on caregivers and their families, reactions towards the illness, types of care available, medications and predisposing factors for developing the disease.

One paper concluded that a psychosocial intervention that contained an educational component could raise caregivers' awareness and recognition of dementia-related behaviours, and subsequently could respond to them more appropriately (Dahlrup, Andrén & Elmståhl, 2011).

Practical Advice

Practical advice was defined as helping caregivers with financial support and planning and signposting for additional resources available. Three of the interventions included these components

as part of the interventions offered (Mittleman, Haley, Clay & Roth, 2006; Andrén & Elmståhl, 2008a; Mittleman, Brodaty, Wallen & Burns, 2008).

In the study by Mittleman, Haley, Clay and Roth (2006) the interventionists provided caregivers with a resource pack containing lists of supporting agencies within the community. In addition to this, they provided information on how to access auxiliary help if required. Furthermore, if the caregivers needed assistance with finances, the interventionists referred them to appropriate services for this. Similarly, the psychosocial intervention described by Andrén & Elmståhl (2008a) included a 'practical session' in which participants were given information about available resources, costs and legislation. It also included planning for respite care, should it be required.

Peer Support

Peer support appeared to be an important component in the interventions offered to caregivers of people living with Dementia. Of the 17 studies reviewed, eight studies included a support group as part of the intervention offered (Andrén & Elmståhl, 2008a; Wang, Chien & Lee, 2012; Chien & Lee, 2011; Andrén & Elmståhl, 2008b; Dahlrup, Andrén & Elmståhl, 2011; Elliott, Burgio & DeCoster, 2010; Belle et al. 2006) and two studies encouraged caregivers to access a support group (Mittleman, Haley, Clay and Roth, 2006; and Mittleman, Roth, Clay & Haley, 2007).

Of those studies where a support group was a component of the intervention, they differed in terms of their formality and structure. The studies by Andrén and Elmståhl (2008a); Wang, Chien and Lee (2012); Chien and Lee, (2011); Andrén and Elmståhl (2008b); and Dahlrup, Andrén and Elmståhl, (2011) provided support group sessions facilitated by a member of staff to cover topics, whereas the studies by Elliott, Burgio & DeCoster, (2010); and Belle et al. (2006) were not facilitated by a member of staff, but were arranged as part of the intervention.

The structured group sessions such as that as described by Andrén and Elmståhl, (2008a) provided emotional support, in which participants were able to discuss the emotional impact of the caregiving role. The aim of these sessions were to enable participants to express their shared feelings

and experiences of anger and sadness, share coping strategies and discuss concerns and worries about the future. Whereas unstructured group sessions or 'conversationalist' groups such as that in Belle et al. (2006) were an addition to the psychosocial intervention to reduce social isolation, and find support from others for making difficult decisions regarding their caregiving role. It also encouraged participants to share their learnt experience from taking part in the psychosocial intervention.

Problem Solving/Behaviour Management

Another component involved helping caregivers to identify strategies to manage difficult or problematic behaviours related to Dementia; this component was variously termed problem-solving, crisis management or behavioural management. This review identified 14 studies that involved interventions aimed at helping caregivers to develop effective strategies to manage difficult behaviours presented by the individual with Dementia (Mittleman, Haley, Clay & Roth, 2006; Gitlin et al. 2008; Davis, Tremont, Bishop & Fortinsky, 2011; Wang, Chien & Lee, 2012; Joling et al. 2012; Chien & Lee, 2011; Andrén & Elmståhl, 2008b; Dahlrup, Andrén & Elmståhl, 2011; Mittleman, Brodaty, Wallen & Burns, 2008; Tremont, Davis, Bishop & Fortinsky, 2008; Elliott, Burgio & DeCoster, 2010; Belle et al. 2006; Gavrilova et al. 2009; Teri, McCurry, Logsdon & Gibbons, 2005).

The study by Teri, McCurry, Logsdon and Gibbons (2005) described a psychosocial intervention aimed at helping each caregiver identify and manage problematic behaviours through a behavioural approach. Participants were requested to keep behavioural diaries, in which the antecedents, problematic behaviours and consequences were recorded. The intervention used a problem-solving approach to help the caregiver modify the antecedents that cause the behavioural difficulties and the consequences that may maintain them. The interventionist and the participant then drew up a behavioural management plan for the caregiver to follow. These strategies were reviewed throughout the intervention.

Psychological Interventions for Caregivers

Psychological interventions aimed at helping the carer deal with emotional aspects of their situation, such as counselling and stress management. Out of the 17 interventions described, seven offered this kind of intervention (Gitlin et al. 2008; Davis, Tremont, Bishop & Fortinsky, 2011; Wang, Chien & Lee, 2012; Chien & Lee, 2011; Elliott, Burgio & DeCoster, 2010; Belle et al. 2006; Teri, McCurry, Logsdon & Gibbons, 2005) and one offered 'ad hoc' counselling (Joling et al. 2012).

Whilst the majority of studies did not describe the psychological support offered in detail, the REACH – II interventions described by Elliott, Burgio and DeCoster (2010) and Belle et al. (2006) incorporated a Cognitive Behavioural Therapy intervention, such as cognitive reframing, increasing pleasant activities in order to reduce caregiver depression and behavioural stress management techniques to reduce perceived burden.

Other

Other intervention components were identified, although were not common across the studies. These included increasing meaningful activity for the person with dementia (Graff et al. 2007) and improving caregiver communication (Teri, McCurry, Logsdon & Gibbons, 2005).

Intervention Modality

Telephone Interventions

As studies are constantly looking to develop interventions that are cost effective, a number of studies involved telephone contacts rather than face-to-face interventions that can be costly and timely. Those studies involving telephone contact can be separated into interventions done solely through the telephone, incorporated in a multimodal method of intervention delivery, and those that use the telephone as an 'ad hoc' addition as part of a larger intervention. Of the 17 interventions reviewed here, 10 involved the use of a telephone to deliver some aspect of the intervention. Of these, two studies aimed specifically to evaluate the effectiveness of a telephone intervention (Tremont, Davis, Bishop & Fortinsky, 2008; Davis, Tremont, Bishop & Fortinsky, 2011); five incorporated

telephone contact on a formal basis, ranging from two contacts through to daily contacts (Gitlin et al. 2008; Andrén & Elmståhl, 2008a; Elliott, Burgio & DeCoster, 2010; Belle et al. 2006; Teri, McCurry, Logsdon & Gibbons, 2005); and three included 'ad hoc' telephone contact if required (Mittleman, Haley, Clay & Roth, 2006; Mittleman, Roth, Clay & Haley, 2007; Mittleman, Brodaty, Wallen & Burns, 2008).

Whilst the majority of these telephone interventions were carried out on an individual basis, the interventions described in the studies by Elliott, Burgio and De Coster (2010) and Belle et al. (2006) incorporated the use of conference calling to deliver telephone support groups, alongside individual intervention components.

Involvement of other family members

Four of the studies described interventions that involved another member of the family besides the primary caregiver (Mittleman, Haley, Clay & Roth, 2006; Mittleman, Roth, Clay & Haley, 2007; Joling et al. 2012; Mittleman, Brodaty, Wallen & Burns, 2008).

For example, in the studies by Mittleman, Haley, Clay and Roth (2006) and Mittleman, Roth, Clay and Haley (2007), they involved the family in problem-solving sessions to determine what strategies would be effective in reducing problematic memory and behavioural problems in the person with Dementia. These studies aimed to improve communication between family members about these issues and to increase social support.

Tailoring Interventions

Although the majority of the interventions were structured, eight of the interventions allowed for flexibility on the part of those delivering the intervention in order to meet the individualised caregiver needs (Davis, Tremont, Bishop & Fortinsky, 2011; Mittleman, Roth, Clay & Haley, 2007; Mittleman, Brodaty, Wallen & Burns, 2008; Tremont, Davis, Bishop & Fortinsky, 2008; Elliott, Burgio & DeCoster, 2010; Belle et al. 2006; Graff et al. 2007; Teri, McCurry, Logsdon & Gibbons, 2005).

The psychosocial intervention described by Belle et al. (2006) identified five different target areas to reduce the risk of the caregiving experience on depression, burden, self-care and healthy behaviours, social support and problematic behaviours. Each of these target areas had specific interventions aimed at reducing their risk. For example, in order to reduce burden, participants were given information on safety, caregiving and stress. They were also taught how to practice three different stress-management strategies, such as breathing exercises, music and stretching exercises. They were also referred to a computerised stress-management program. Each caregiver was assessed to identify the risk for each of these target areas, and an individualised intervention package was compiled and tailored to meet the individual caregivers need.

The Effectiveness of Interventions for Caregivers caring for People with Dementia

The second focus of this literature review was to assess the effectiveness of these multicomponent intervention packages on; 1) the impact on the caregivers general psychological well-being and quality of life, 2) the impact on the caregiver's response to challenging behaviour, 3) the impact on move to residential care and 4) the impact on the mood and behaviour of the person with dementia.

Impact on caregivers' general psychological well-being and quality of life

Sixteen of the studies reported outcomes in relation to the impact on the caregivers' general psychological well-being and quality of life. Of these, twelve reported significant outcomes for caregivers' general psychological well-being and quality of life. For example the psychosocial intervention carried out by Andrén and Elmståhl (2008a) showed significant reductions in burden at both the follow-up at six months and twelve months.

However, not all of these studies showed a significant outcome. For example, in the study by Davis, Tremont, Bishop and Fortinsky (2011) they highlighted that whilst the telephone intervention reduced feelings of guilt, the intervention did not have a significant impact on the reduction of caregiver reported anxiety, depression or improvement in health at three month follow-up. Similarly,

the psychosocial intervention carried out in the study by Gitlin et al. (2008) did not show any significant improvements in depression or burden scores at four month-follow up. Furthermore, the intervention from Joling et al. (2012) did not significantly reduce anxiety, depression or burden at three and six month follow-up. However, in two of these studies they had small sample sizes, and one did not meet power.

Furthermore, the intervention described by Joling et al. (2012) had a distinctive difference to the other interventions. This intervention involved family meetings, with the aim of enhancing social networks and improving emotional support. It may be that this intervention may not have significantly impacted upon the caregivers' reports of anxiety, depression and burden, but it impacted upon other variables.

Out of those 12 that showed a significant outcome, six had follow-up periods ranging from six weeks to six months and only six included a follow-up period of at least twelve months. Those with a longer follow-up period did tend to show that the impact on caregiver wellbeing and quality of life persisted to follow-up. For example, in the study by Chien and Lee (2011) they found that a comprehensive dementia care family program, which involved peer support, psychoeducation, problem solving and psychological support had significant improvements in caregiver burden and quality of life at eighteen month follow-up.

Impact on carer's response to challenging behaviour

Out of the 17 studies, five reported significant outcomes for impacts on the caregivers' response to challenging behaviour (Mittleman, Haley, Clay & Roth, 2006; Wang, Chien & Lee, 2012; Dahlrup, Andrén & Elmståhl, 2011; Graff et al. 2007 and Teri, McCurry, Logsdon & Gibbons, 2005).

In the study by Wang, Chien and Lee (2012) they found that following the psychosocial intervention, the caregivers reported having better insight into dementia related behaviours and reported being more confident in managing and problem solving difficult behaviours. Similar findings were found by Dahlrup, Andrén and Elmståhl (2011) suggested that by increasing a

caregivers understanding of dementia and typical behaviours to expect, the caregivers would be more likely to develop appropriate and effective strategies in being able to manage them more effectively.

Out of these five papers, only one included a long term follow-up (Mittleman, Haley, Clay & Roth, 2006). They found that the psychosocial intervention had significant improvements in caregivers' satisfaction with social support, response to patient behaviour problems and reductions of depressive symptoms at four, eight and 12 month follow-up.

Impact on move to residential care

Out of the 17 studies, four evaluated the impact of the interventions on the length of time the caregiver was able to continue care in the community before having to move their loved one to residential/nursing accommodation (Andrén & Elmståhl, 2008a; Belle et al. 2006; Mittleman, Haley, Clay & Roth, 2006; Chien & Lee, 2011). All four studies, apart from Belle et al. (2006) reported a significant impact of the intervention on rates of admission to residential/nursing accommodation. For example, in the study by Mittleman, Haley, Clay and Roth (2006) those participants who were assigned to the multi-component psychosocial intervention were able to care for their loved one with Dementia at home for longer in comparison to a control group. Those in the treatment group cared for the person in the community for an average of one thousand and sixty six days compared to the control group, who placed their loved one with Dementia into residential care after an average of one thousand one hundred and eighty one days. Belle et al. reported an advantage to the intervention group, but the difference was not significant.

Impact on mood and behaviour of the person with dementia

Whilst the psychosocial interventions primary outcomes were aimed at the caregiver, five of the studies included measures to monitor the impact on the mood and behaviour of the person with dementia. Of these, three identified significant positive outcomes for those with dementia (Chien & Lee, 2011; Graff et al. 2007; Teri, McCurry, Logsdon & Gibbons, 2005) whilst Gavrilova et al. (2009) found that the psychosocial intervention had no significant difference on the quality of life for

the person with dementia. The study by Gitlin et al. (2008) did show positive outcomes for those with dementia, but these results were not significant.

For example, in the study by Chien and Lee (2011) they found that the psychosocial intervention had a significant impact on the severity and frequency of the dementia related symptoms, including symptoms of delusions, agitation, aggressive behaviours and hallucination-related behaviour at an 18 month follow-up when compared to a control group. The authors suggested that by improving the quality of life of the caregiver and reducing their experience of burden, caregivers are able to provide better care for those with dementia, which subsequently impacts upon the severity of the disease.

The majority of these studies had short follow-up intervals of between six weeks and six months, and only one had follow-up interval at eighteen months (Chien & Lee, 2011). Therefore it is difficult to ascertain whether these significant outcomes have long lasting effects.

Moderating Variables

A number of moderating variables on successful outcomes were identified in the studies, including social support (Mittleman, Roth, Clay & Haley, 2007; Mittleman, Haley, Clay & Roth, 2006) severity of dementia (Mittleman, Haley, Clay & Roth, 2006; Andrén & Elmståhl, 2008b) poor caregiver health (Mittleman, Haley, Clay & Roth, 2006) financial income (Mittleman, Haley, Clay & Roth, 2006) relationship type (Andrén & Elmståhl, 2008a) and ethnicity (Belle et al. 2006).

For example, whilst Mittleman, Roth, Clay and Haley (2007) found that the psychosocial intervention had significant outcomes for caregivers' self-reported health, this result was mediated by the caregivers' satisfaction with the increased social support they received from partaking in the intervention. This suggest that whilst the intervention was aimed at improving the health outcomes for the participants, involving family members in the intervention led to more satisfaction with social and emotional support, which subsequently improved health outcomes. In addition, in the study by Andrén and Elmståhl (2008a), they found a significant result for those participants in the intervention

group where the severity of the dementia was rated as mild to moderate. However, the intervention did not have any significant influences on those caregivers where the symptoms of dementia were severe.

DISCUSSION

Although each of the studies described multicomponent psychosocial interventions, there were specific commonalities in the components shared between them, including psychoeducation, practical advice, peer support, psychological interventions, and problem-solving techniques. The review also indicated that these components could be delivered directly to the caregiver, in a group format, over the telephone or involves family caregivers. Some studies delivered the same package to all participants, whereas some tailored their interventions to the particular needs of each caregiver.

When evaluating the effectiveness of the multicomponent psychosocial interventions, this review identified four common outcomes measured by the studies including the impact on the caregivers' well-being and quality of life, the caregivers' responses to dementia-related memory and behavioural difficulties, the impact on the move to residential care and the influence on the person with dementia.

The review also identified specific moderating variables that could influence the significance of the outcome, including the severity of the dementia, the caregivers' satisfaction with social support and ethnicity.

This review was an extension of the previous review carried out by Selwood et al (2007). The review by Selwood et al. (2007) concluded that 'individual behavioural management techniques', 'individual coping strategies' and 'group coping strategies' interventions were significantly more effective in reducing the caregiver burden and depression scores than any other type of interventions. The current review found significant outcomes for caregiver burden and depression for 12 of the 16 interventions that explored these outcomes. Of these, three of the interventions included 'individual behavioural management techniques' and two included 'group coping strategies' which supports the

findings by Selwood et al., (2007). The remaining effective interventions in the current review fell into categories of intervention that were not included in the earlier review. Five of these were 'family-based interventions' and two were 'tailored interventions'. These appear to represent developments in the way in which interventions are delivered. Four of the papers reviewed in the current review did not find a significant effect on caregiver depression or burden. Two of these involved interventions over the telephone (Tremont, Davis, Bishop & Fortinsky., 2008; Davis, Tremont, Bishop & Fortinsky, 2011), and the other two were focused on behavioural management (Gitlin et al., 2008; Joling et al., 2012). However, as previously discussed these four studies had significant limitations in their design, such as lack of power. The delivery of the interventions by telephone could also explain the lack of effect. Unlike Selwood et al., (2007) who reviewed single-component studies, the interventions in the current review were all multi-component, and thus only tentative comparisons can be made.

The conclusions about effectiveness of the interventions should be viewed with caution as all of the findings of the current literature review are limited by the varied quality of the evidence. Of the 17 studies reviewed, the overall quality ratings ranged from 15 to 24 out of a possibly 30, with only eight scoring above 20 (see Table 1.3). Whilst all of the studies had specific limitations, any studies that scored lower than 20 are of a poorer quality and thus any findings or conclusions drawn from these studies may be a reflection of a design flaw rather than the intervention itself. There is a definite requirement for better quality intervention studies within this field for appropriate conclusions to be made regarding their effectiveness.

The relationship between the caregiver and the person with dementia is becoming increasingly recognised as an important influence on outcome. Based on a review of the literature on this topic, Ablitt et al. (2009), suggested that the quality of the premorbid relationship between the caregiver and the person with dementia prior to its onset, determines the form the relationship takes during the caregiving experience. They also concluded that if the quality of the relationship is

maintained, and both the caregiver and the person with dementia experience mutuality, the quality of the relationship may buffer against the adverse and negative effects associated with the caregiving role. Similarly, based upon qualitative research, a study by Riley et al. (2013) emphasised the importance of the relationship and developed a tool that could quantitatively measure the caregivers' perception of whether the relationship was continuous of a loving and meaningful relationship or discontinuous and changed. In this review, none of the psychosocial interventions described focussed upon the caregivers' experience of the quality of the relationship between themselves and the person with dementia. Given the recent trend in research to focus upon the relationship, this review suggests that future intervention studies should focus on interventions aimed at enhancing the relationship between the caregiver and the person with dementia.

The majority of the research within this review is focussed on the caregiver's well-being and quality of life as a primary outcome, and little attention is paid to the impact of the interventions on the person with dementia, and even less on the relationship between the two. Given that there is strong evidence that indicates that the quality of the relationship can subsequently impact upon the quality of the care the caregiver provides, having important implications for the person with dementia, it is important that future studies evaluate the impact of their interventions on the person with dementia and on the relationship.

As all of the studies evaluated the effect of multicomponent interventions and none evaluated the effects of individual components. It is therefore unclear which of the components are necessary or more effective than others. Interestingly, in the systematic literature review by Selwood, Johnston, Katona, Lyketsos and Livingston (2007) they found that psychoeducation alone was not an effective intervention. Despite this, the majority of studies in this review included psychoeducation in the multicomponent interventions.

The interventions described in this review had very few theoretical underpinnings. The Medical Research Council outlined a framework for both the development and evaluation of

intervention based studies (Campbell et al., 2007). The authors placed emphasis on the requirement of good quality intervention based studies being driven and developed from theory in order to improve health care standards. This review suggests that intervention studies in this context in the future would need to be designed on the basis of a more thorough understanding of the challenges within the caregiving experience for those with dementia, and interventions should be designed specifically at meeting those challenges. For example, the literature on what happens to the relationship as the couple try to cope with the challenges of dementia (Ablitt et al. 2009; Riley et al. 2013) could be used as a guide to develop interventions that attempt to improve the relationship, and thereby lessen the impact of these challenges on both the caregiver and the person with dementia.

All of the studies identified by the literature search met at least half of the criteria of quality as rated by Downs and Black's (1999) quality framework, but there was significant room for improvement in most of them. Each of the studies obtained high ratings for the quality of reporting and the majority successfully met power. However, there was considerable variability in the overall quality ratings for the internal validity of each of the studies. The studies in this review consistently failed to control for selection bias and confounding variables. In addition to this, with the exception of one study, none of the studies met the criteria for a double-bind study thus increasing the likelihood of experimenter bias. Furthermore, each of the studies scored poorly for external validity, meaning that the findings could not be generalised to a larger population. Sample sizes in some studies were also too small to detect all but large effect sizes.

For example, the study by Gitlin et al. (2007) found that the intervention was not statistically significantly different for caregiver well-being and quality of life, or the mood and behavioural difficulties of the person with dementia when compared to a control sample. This study consisted of thirty participants in each of the conditions, and whilst the study did meet power to detect large effect sizes, it fell short of being sufficiently powered to detect more modest effects. This study did show a

trend towards positive outcomes for both the caregiver and the person with dementia, and therefore, it is plausible that with a larger sample, these findings would be statistically significant.

In addition to this, the length of time between follow-up varied across studies. A large proportion of these studies had follow-up evaluations at approximately six months, and thus could only determine short-term effectiveness of the interventions. Given that the severity of the symptoms of dementia is likely to increase as the disease progresses, it is important to examine the effects of interventions over a longer time period to determine their long-term effectiveness. Whilst seven of the studies (see Table 1.2) did evaluate the effectiveness of the interventions beyond a one-year follow-up, and did show significant differences between the intervention group and the control group, the need for longitudinal studies in this area is necessary and an important implication for future research.

Whilst some of the studies investigated moderating variables such as ethnicity and the severity of the dementia, the majority did not. It is important for future research to identify potential moderating variables as this will determine what intervention works for whom and when. This will enable interventions to be developed with components designed specifically to target those who are most likely to respond to them, subsequently being more cost-effective without wasting resources by giving individuals treatment components that may be unlikely to benefit them.

In the review by Pinquart and Sörensen (2007) they concluded that those interventions that were tailored to the individual needs were the most effective. Fewer than half of the interventions in this review attempted to adapt the intervention to meet the needs of the individual with positive outcomes for the caregiver. Future research should be focussed upon developing interventions that are tailored to the needs of the caregiver in order to be flexible and adaptable to the changing needs of the caregivers.

This literature review recommends that studies examining the effectiveness of interventions for caregivers of those with dementia should focus on developing interventions that stem from a

theoretical framework, identify moderating variables that could lead to the development of optimal interventions and should focus on tailoring them to each individual caregivers situation rather than being a one-size-fits all. Furthermore, improvements in the quality of study design are required, such as larger samples and ensuring that the sample is representative of the relevant population and settings.

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PAPER 2

Empirical Paper

REACTIONS TO CARING FOR A SPOUSE OR PARTNER WITH DEMENTIA

Are perceptions of relationship continuity associated with emotional responses to providing care to a spouse with dementia?

ABSTRACT

Background: The following paper describes a small-scale research study designed to quantitatively assess the association between the caregivers' perception of the relationship, and their overall experience of caregiving for their spouse with dementia. Caregiving has been found to have both positive and negative outcomes for caregivers of people with dementia. Recently research has focussed upon identifying moderating variables that can determine the outcome of the caregiving experience. This study is grounded in qualitative research that has indicated a link between the perceived continuity of a meaningful and loving relationship with more positive experiences of caregiving, whilst negative outcomes have been related to perceived discontinuous, changed or lost relationships. A recent measure, developed at the University of Birmingham, allows for these claims to be examined in a quantitative design.

Method: Sixty-nine caregivers participated in the research study. They were requested to complete the Birmingham Relationship Continuity Measure, the Zarit Burden Inventory and the Positive Aspects of Caregiving scale. Correlations were carried out to determine if there was an association between relationship continuity and the experience of caregiving.

Results: The study found that those caregivers who perceived their relationship as continuous of a loving and meaningful relationship were more likely to experience positive aspects of caregiving and less burden. The findings support the claims of previous research.

Conclusions: The limitations of the study were discussed and both the research and clinical implications of this research have been outlined. The research proposes that interventions should be aimed at enhancing the relationship between the caregiver and the person with dementia, as this will not only have benefits for the caregiver, but will also impact upon the well-being of the person with dementia.

INTRODUCTION

Caregivers are defined as: 'Spending a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems' (Department of Health, 2008, p. 11).

In 2001, the national census review found that there were six million people across the U.K. who identified themselves as an informal carer (Office for National Statistics, 2001). This number increased by 10% in 2011 (Valuing Carers, 2011). It has been estimated that 1.5 million carers are over 50 and that 18% of these are caring for a spouse (Office for National Statistics, 2001). It has been suggested that the spouse is usually responsible for the community-based care of older adults (Lewis, 1998). The current national economic value of the contribution made by informal carers in the UK is £119 billion per year (Valuing Carers, 2011). This is significantly more than the £98.81 billion overall annual spend of all aspects of the NHS during the 2010 – 2011 fiscal year (Valuing Carers, 2011).

In 2012 the Alzheimer's Society released a report which stated that with an estimated 800,000 people diagnosed with Dementia, Dementia care is one of the largest costs to the NHS, local authorities and families, costing approximately £23 billion per annum (Dementia 2012: A National Challenge, 2012). It also indicated that a large proportion of people living with Dementia were being cared for informally by approximately 670,000 family members acting as a primary caregiver (Dementia 2012: A National Challenge, 2012). In the National Dementia Strategy in 2009, they estimated that due to an ageing population, with higher longevity, the number of people expected to have a diagnosis of a Dementia has been predicted to rise to 1.4 million in 2038. Due to this increase, it is estimated that Dementia care will cost the government approximately £50 billion by 2038 (Department of Health 2009).

Given that informal carers save the government a large proportion of money, the need for informal carers caring for people with Dementia at home is increasing. However, there is a growing crisis for the government, and the NHS, as there is a mismatch between the amount of carers and those needing care. It has been suggested that within the next four years, the number of people needing care will be greatly higher than the number of people able to provide that care (Pickard et al. 2008).

A meta-analysis by Vitaliano, Zhang, amd Scanlan (2003) indicated that caregiving is chronically stressful and can have negative and adverse effects on the caregivers' psychological, emotional and physical well-being. They found that caregivers had 23% more stress hormones, higher blood pressure and an increased level of glucose than non-caregivers. Other physical health effects have been noted such as difficulties sleeping, headaches and weight gain or loss (Van Exel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005). Furthermore, a study by Lai (2012) indicated that the perceived financial cost implications of caregiving for an older adult increased the levels of burden reported. Caregivers often find it stressful to manage employment alongside the caregiving role, this was highlighted in a study by Schulz et al. (2003) who indicated that often caregiving for an elderly relative can amount to a full-time job and lead to increased periods of absence from work. The IPSOS poll also indicated that 1 in 5 informal caregivers eventually leave their employment (Department for Work and Pensions and Carers UK, 2009). The prevalence rates of depression and a feeling of burden amongst spousal caregivers of older adults significantly increases (Murray, 1995). In a study by Murray and Livingston (1998) they suggested that spousal carers are at a higher risk of developing depression than age-related peers who do not perform a caring role.

A number of variables could account for why caregiving has such detrimental effects upon the caregiver and lead the individual to feel a greater sense of caregiver burden. Caregiver burden is defined as the caregiver's perceived level of distress, the demands placed upon them and the pressures associated with the caregiving role, responsibilities and tasks (Gitlin et al. 2003). It has been

suggested by Schulz et al. (2002) that many carers feel a sense of entrapment by their caregiving role. It can disrupt the caregivers social time with friends and family (Parrish & Adams, 2003). Caregivers can often experience higher levels of guilt, especially when they are relinquishing their caregiving role to a professional carer (Kaplan, 2001). Furthermore, it has been suggested that spousal caregivers experience greater self-sacrifice than adult-child caregivers (Ott, Sanders & Kelber, 2007).

Whilst caregiving can be a burdensome and a negative experience for some caregivers, findings indicate that the caring role can be positive if a carer finds meaning and reward in looking after his or her partner (Metenko, 1998). In a study by Giunta (2004) she found that the majority of caregivers expressed they felt that they were making a significant contribution to their loved one. In a study by Tarlow et al. (2004) they reviewed 14 quantitative papers that included measures for positive aspects of caregiving. The overall findings of this review suggested that caregivers experience satisfaction with their caregiving role irrespective of the burdens or demands placed upon them, highlighting the complexity of the caregiving process. It has been found that when caregivers are satisfied with their caregiving role they may experience a reduction in stress and improvements in their psychological and emotional well-being (Roff et al. 2004).

In a study by Cohen, Colantonio and Vernich (2002) they found that 73% of caregivers could identify at least one positive aspect of caregiving. These ranged from feeling fulfilled, responsible, important or finding a sense of companionship and meaning within the relationship. They also found that those who reported higher positive aspects of caregiving reported less depression, burden and had better subjective health than those who did not. These findings suggest that the ability to identify positive aspects to the caregiving role, may act as a buffer against negative consequences.

A number of variables have been identified in determining whether a caregiver experiences positive or negative aspects of caregiving, such as the individual's coping style (Connell et al. 2001) or their individual personality type (Koerner & Kenyon, 2007). It has been thought by Tarlow et al. (2004) that caregivers appraise their caregiving experience by weighing up both the positive

experiences of caregiving against the negative demands placed upon them. They suggest that the positive aspects of caregiving can act as mediators to reduce the stress experienced and enhance the caregivers' quality of life. They suggest that whilst the caregiver may have to assist the person with Dementia with activities of daily living (ADL) rather than viewing this as a negative or burdensome experience, they perceive it as the extension of a reciprocal relationship and giving back something to someone they love. This in turn increases the caregivers' life satisfaction and self-esteem.

Research within Dementia care has gone through three-distinct phases as identified in a meta-analysis by Ablitt, Jones and Muers (2009). Initial research focussed on the experiences of the carer. Subsequently, this shifted to research on the experiences of the person with Dementia. More recently research has focused upon the importance of the relationship between the person living with Dementia and their carer. When one person in a relationship develops dementia, there are inevitable changes in the way that the couple interact. Many different dimensions of the marital relationship change, including approaches to household tasks, companionship, affection and intimacy (Wright, 1993; Kaplan, 2001), reflecting the dependency of the person with dementia (Garand et al. 2007).

The quality of the relationship may also impact on how the carer and the person with dementia respond to the challenges of dementia. Kitwood (1993) developed a model of person-centred care, albeit in the context of the relationship between people with dementia and paid carers. This stressed how the quality of the relationship not only improved carer well-being but also had a positive impact upon the symptoms of Dementia. Furthermore, Burgener and Twigg (2002) carried out a longitudinal study with spousal caregivers and the person with Dementia, and found that the perceived quality of the relationship predicted fewer declines in the person with dementia. In addition, it has also been found that a good quality relationship can reduce the stress and burden levels for the caregiver. In a study by Stedmon, Tremont and Davies (2007) they found that carer satisfaction with the relationship was associated with less burden, fewer reactions to memory and behaviour difficulties and more effective problem solving.

The quality of the caregiving relationship can be shaped by numerous factors, such as the quality of the premorbid relationship (Steadman, Tremont & Davies, 2007). If the caregiver perceives the relationship prior to the onset of dementia as loving and reciprocal, they are less likely to experience feelings of burden when caregiving for that person. However, if they view the premorbid relationship to be negative, they are more likely to resent the caring role they have been placed in and feel entrapped.

A study by Riley et al. (2013) stressed the importance of relationship continuity as another factor that can shape the caregivers experience of the caregiving role. The authors suggest that caregivers perceive their relationship with their spouse as either continuous or discontinuous of their premorbid relationship. In this context, continuity is defined as the caregivers' perception of a loving relationship being maintained despite the inevitable changes associated with dementia. Discontinuity, on the other hand, refers to the caregivers' perception of a once loving relationship as changed, replaced or lost, with someone who no longer resembles their partner. A quantitative measure was developed at the University of Birmingham by these same authors, namely The Birmingham Continuity and Relationship Measure (BCRM). This measure is a 23 item questionnaire, and was developed from continuity themes identified in previous qualitative literature. The measure comprised of items that capture the five domains identified from previous literature, namely 1) Relationship Redefined, 2) Same and Different Person, 3) same and Different Feelings, 4) Couplehood and 5) Loss.

A number of qualitative studies have suggested that relationship continuity or discontinuity may be associated with how well the spousal carer responds emotionally to the caregiver role and the demands placed upon them. Specifically, these studies have identified a relationship between the degree of continuity and the extent of burden or positive aspects of caregiving the caregiver reports. It has been suggested that spousal caregivers who report relationship continuity is associated with more satisfaction, gratification and meaning from the caregiving role (Chesla Martusan & Muwases

1994; Motenko, 1989; Murray et al. 1999) as well as feeling more empathy with the individual with Dementia (Walters et al. 2010). In a study by Murray and Livingston (1998) they interviewed 307 spousal caregivers of individuals with a severe and enduring Psychiatric condition (including Dementia). The themes identified in this study suggested that the spousal caregivers perceive the relationship between themselves and their partner as either discontinuous or continuous, and this determined how tolerant they were of difficult or challenging behaviours associated with their partners' condition. The study suggested that some spousal caregivers see their spouse as an object or shell of their former self and no longer perceive their partner as their partner. In these instances, the spousal caregivers experienced more burdens and struggled to tolerate challenging or difficult behaviours. On the other hand, the authors found that some caregivers still perceived continuity in the relationship and were able to view their spouse as the same person, irrespective of their condition. In these instances, the authors found that the spousal caregivers were more likely to tolerate difficult behaviours.

Similarly, Motenko (1989) interviewed 50 female spousal caregivers caring for their husbands with Dementia. The author found that those spousal caregivers who experienced the same marital closeness following the onset of Dementia reported greater satisfaction and gratification with the caregiving role than those who experience discontinuity in the relationship, despite the burdens endured. They also found, that caregivers expressed gratification with their caregiver role irrespective of the type of relationship prior to the onset of the Dementia. For example, those wives who did not have a close relationship with their partner's pre-onset of the Dementia still showed greater gratification with their caregiving role if the relationship continued to be the same. The author suggests that continuity is important in the meaning of the caregiving role, for example, wives may wish to provide care in order to reciprocate the love, affection and attention their partner previously gave them, and view their caregiving role as the continuation of a meaningful, loving and enduring relationship. The author also indicated that wives who perceived their relationship as discontinuous

were more likely to provide care out of an act of duty and responsibly, and perceived their caregiving role as the end of the marital relationship. The author suggested that the latter wives are more likely to experience burdens as opposed to gratification.

Whilst continuity has been associated with more satisfaction from the caregiving role, by contrast, qualitative studies have indicated that discontinuity has been associated with greater feelings of burden, such as feelings of entrapment (Walters et al. 2010) as well as an increase in negative reactions to challenging behaviours (Murray and Livingstone, 1998; Walters et al. 2010). A qualitative piece of research interested in caregivers' understanding of and responses to their partners with Dementia was carried out by Walters et al. (2010). In this study they interviewed six spousal caregivers regarding their perceptions on the caregiving relationship and their experience of caregiving. The study identified numerous themes relating to continuity and discontinuity including same or different person, relational change, emotional responses to behaviours, and impact on day-to-day life, and suggested that the caregiver's sense of continuity influenced each theme. The authors suggested that those who viewed their spouse as different tended to depersonalise, use objectifying language and describe them in a negative way. Whereas other caregivers were able to view characteristics in their partner that were fundamentally the same, such as a sense of humour, and this seemed to help the caregiver minimise the impact of the inevitable Dementia-related changes. In these instances, the caregivers sought continuity in order to minimise the distress experienced as the disease deteriorated. The study identified that caregivers were either able to assimilate relational change or completely re-define their relationship dependent upon the context of their premorbid relationship. It was suggested that in some instances the relationship boundaries between the caregiver and their spouse shifted from love and affection to protection and care, as the dementia became central to defining their relationship. In these instances the authors suggest that the caregivers act out of a sense of duty, rather than from love and affection. This study identified that relational change could be attributed to the amount of behaviour difficulties experienced. The authors also

identified that caregivers experience either guilt or empathy for the person with Dementia. Caregivers experienced more guilt in relation to the degree and severity of the behavioural difficulties exhibited by their partner, and in order to manage this feeling the caregivers may remove their sense of personal agency. On the other hand, it was reported that caregivers would often try to understand their partners' behaviours, as a means of reducing their frustration with the situation. The authors suggested that those caregivers who viewed the relationship and the individual as continuous are more likely to be person-centred in their approach than those who do not. The authors also concluded that if the impact of the Dementia impacted upon their continuity or discontinuity with everyday activities this had the potential to cause the individual to feel entrapped in the caregiving role with no freedom to pursue their own independence.

By interviewing 15 spouse caregivers and 15 child caregivers Chesla, Martusan and Muwases (1994) suggested three types of relationships following the onset of Dementia. The first type they identified was a relationship that is still continuous, where the relationship continues on from the previous relationship. The second type of relationship was named 'continuous but transformed' where the relationship is seen as still there, but is less reciprocal. The final type of relationship was named 'radically discontinuous', where although the care provided remains good, the relationship is distanced and loss of emotional connection.

The research regarding the connection between relationship continuity and the caregivers experience of either positive benefits to their caregiving role or negative emotional, psychological and physical responses associated with burden, has been exclusively qualitative. Given the nature of qualitative research, the generalizability of these findings is unclear. The aim of the current study was to test the suggestions, arising from qualitative studies, in a quantitative study using questionnaires. In the study by Riley et al. (2013) a reliable measure of relationship continuity was developed for this very purpose. By using this measure, it is hoped that the connection, between relationship continuity

and the caregivers' emotional experience of the caregiving role, will be strengthened by the quantitative evidence.

The study hypothesised that those caregivers who reported higher relationship continuity will report more positive aspects of caregiving and fewer burdens associated with caregiving. Whilst those caregivers who reported relationship discontinuity will report more negative responses and fewer positive aspects of caregiving associated with caregiving.

METHOD

Ethical considerations

The study obtained ethical approval from the Solihull Research Ethics Committee (see Appendix B).

All of the participants received a participant information booklet (see Appendix B) prior to consenting to the study. This contained information to ensure that participants were fully informed as to the purpose of the study, why they were being requested to take part, what the study will entail, any benefits to taking part of the study and any adverse effects of partaking in the study. It also explained the participants' rights within the study, for example their right to withdraw at any time. Participants were advised that they could stop completing questionnaires if they found them upsetting and that they were under no obligation to return them. In addition to this, participants were informed that any identifiable information would be kept confidential. All identifiable information was removed from the data and stored separately and each participant was given a number.

In addition to this, as some of the items on the questionnaires were of a sensitive nature and potentially upsetting the participant information sheet provided caregivers with the contact details of local voluntary support agencies they could access if they required. In addition to this, participants were advised to contact the researcher if they felt they needed help in accessing additional support. Upon consenting to the study, the informed consent form contained a clause that if the researcher felt

that the caregiver well-being had been affected by the study, that they could contact the G.P. on the caregivers' behalf or encourage the caregiver to seek formal support (see Appendix B).

Each participant was requested to sign an informed consent form stating that they fully understood the purpose of the study, their rights within the study and that they agree to partake in the study. The informed consent form must be signed and returned, with the questionnaires, if they are to be accepted into the study.

Participants

Recruitment Process

Participants were recruited via volunteer sampling, between January 2014 – April 2014, from six different recruitment sites; two NHS Older Adult Services, the Alzheimer's Society, a local voluntary charity, a housing organisation and a church group. The recruitment of participants involved three different strategies, outlined below:

1) Advertisements for the study (see Appendix B) were placed at each recruitment site, aimed at those seeking support and information about dementia. For example, for the Alzheimer's Society, the local voluntary charity, the housing organisation and the church group, the advertisement was placed on a message board and handed out during the carer's groups. At the NHS sites, the advertisement was placed at outpatient clinics and handed out during the carers groups offered. Potential participants were requested to telephone or e-mail the researcher for further information on the study or to express an interest in participating. If the potential participant agreed to take part, the participant information pack, informed consent form and questionnaires were sent to the participant in the modality of their choice i.e. by post or via e-mail. Pre-paid envelopes were provided to ensure no financial cost was incurred for the participant.

2) The second method of recruitment relied upon local collaborators (employed either within the NHS or within the voluntary agencies). In these instances, potential participants were given information about the study in the form of the participant information booklet and asked if they are willing to be approached by the researcher. Potential participants were required to write down their contact details and sign a 'consent to contact' form (see Appendix B), which gave the researcher permission to contact the potential participant. Following this, the researcher contacted them through the method of their choice (either telephone or e-mail) to answer any questions they may have. Those willing to participate were then sent the informed consent form and questionnaires through a modality of their choice i.e. by post or via e-mail. Pre-paid envelopes were provided to ensure no financial cost was incurred for the participant.

3) The researcher attended carers groups facilitated by the Alzheimer's Society, the local voluntary charity, the housing organisation and by the church. At the local collaborators discretion potential participants were either handed an advertisement or they attended a talk provided by the researcher. The researcher was available at a specific time and location to be approached by participants for further information. In these instances participants could either complete the questionnaires instantly, or were handed a research pack to be returned by post, or could request electronic copies of the questionnaires to be sent through e-mail. Pre-paid envelopes were provided to ensure no financial cost was incurred for the participant.

Obtaining informed consent

Potential participants will receive the participant information sheet before they decide whether or not they wish to take part. The sheet explains why the study is being done, why they have

been requested to take part in the study, and what will be required of them. It also outlines the possible risks and benefits from taking part in the study, outlines their right to withdraw at any time, and makes clear how their data will be kept confidential and secure. Participants will also be given the chance to ask the researcher any questions they have about the research before they agree to take part.

After receiving the information sheet and having the opportunity to ask questions, the participant will then be asked to complete the consent form. The form requests the participant to tick a box to show that they have understood the purpose of the study, their role within the study and their rights to withdraw. It also requests them to tick a box if they wish to have the summary of the research at a later date**.**

Inclusion Criteria

In order to be included in the study participants were required to be the primary caregiver of individual's with a definite diagnosis of dementia (diagnosed at least 6 months prior). As the BRCM is a measure of spousal/partner relationships, the study was limited to spousal caregivers. The caregiver had to be living with the person with dementia in the community, and their relationship had to pre-date the diagnosis of dementia by at least 5 years. The measures of the positive aspects of caregiving and negative burden were only applicable if the person was providing a substantial amount of care to the person with dementia.

Assistance was offered to those who had sensory or motor difficulties with reading or writing, so they were not excluded.

Exclusion Criteria

Participants were excluded from the study if they were unable to provide meaningful responses to the questionnaire items because of cognitive deficits. Furthermore, as the study did not have funding for interpreters, those whose command of English was not adequate to understand the questionnaire items were also excluded.

The potential participants' suitability to partake in the study was determined by the researcher during the initial contact prior to sending out the questionnaire pack.

Sample Size Calculation

A power calculation was conducted using the G*POWER program (version 3.1.3; Faul, Erdfelder, Lang & Buchner, 2007). The main analysis involved correlations. With alpha set at .05 (two-tailed) and the required power at .80, the calculation indicated that a sample of 29 would be required to detect a large effect correlation (r=.5) and a sample of 84 to detect a moderate correlation (r=.3). Because the research is in an area in which each variable is influenced by a wide range of other variables, large correlations were not expected. The aim was, therefore, to recruit at least 29, but as near to 84 as was possible in the time available.

Design

This was a single within-group design study that investigated the correlation between variables measured by questionnaires.

Procedure

Participants were required to complete a demographics sheet as well as three questionnaires that measured relationship continuity, negative aspects of caregiving (burden) and positive aspects of caregiving.

Measures

Birmingham Relationship Continuity Measure (BRCM) –

The BRCM was developed at the University of Birmingham in order to measure the concept of relationship continuity (Riley et al., 2013). The BRCM consists of 23 items that require participants to rate how strongly they agree or disagree on a 5-point Likert Scale. The items are organised into 5 different constructs that measure relationship continuity as indicated in qualitative research that has addressed this issue. These included Same or Different Person (‘*Compared to how he used to be, he's a different person altogether now’)* Relationship Redefined, (‘*I feel like his carer*

now, not his partner'), Same or Different Feelings (*'I care for him, but I don't love him the way I used to'),* Couplehood *('We still do things together that we both enjoy') and* Loss *('I miss having someone to share my life with').*

The BRCM was found to have good internal reliability with an overall Cronbach's alpha level of .95 and good test - re-test reliability (.93) (Riley et al. 2013). Each construct subscale also had good internal consistency; Same or Different Relationship (.70), Same or Different Person (.87), Same and Different Feeling (.89) and Sharing Togetherness (.75) except Loss (.90) that had excellent internal consistency.

Positive Aspects of Caregiving (PAC) –

The Positive Aspects of Caregiving measurement was initially used as a battery of instruments for The Resources for Enhancing Alzheimer's Caregiver Health (REACH; 1995) project. It was adapted by Tarlow et al. (2004) to develop a new independent measurement. The PAC consists of 11 statements regarding the caregivers' emotional response to their caregiving experience. Caregivers are presented with 11 statements, such as 'Providing help to my partner has made me feel appreciated'. Caregivers are requested to rate on a 5-point Likert scale how strongly they agree or disagree with each statement.

The scale is reported to have good inter-item reliability (Cronbach's α =.89). The scale is made up of two factors; Self-Affirmation and Outlook on Life, however as these two factors are highly correlated (.69) it supports a summary score being used.

The Zarit Burden Inventory (ZBI) –

The Zarit Burden Inventory is one of the most common tools to measure caregiver burden. The ZBI require participants to rate, on a 5-point Likert Scale, 22 statements relating to caregiver burden, such as 'Do you feel angry when you are around your relative?'. Participants are requested to rate how often they feel that way from *'Never'* to *'Nearly Always'*. The questions cover several

domains relating to caregiver burden such as health, psychological well-being, financial difficulties, social support and the relationship between the caregiver and the person living with dementia.

The ZBI has shown excellent internal reliability with a Cronbach's alpha level of .93 and good test - re-test reliability (.90) (Seng et al. 2010).

Demographics –

Participants were also asked to complete a demographics sheet in order to identify participants' gender, age, ethnicity, nationality and length of time caregiving to determine if these variables influenced the statistical analysis.

RESULTS

Preparing the data for analysis

The data were inspected prior to analysis for any potential problems. There were no missing data, and no outliers. The Kolomogorov-Smirnov test was used to evaluate whether the distributions of the total scores on each variable departed significantly from the normal distribution. All three totals showed a significant departure (Table 2.1), with evidence of a bimodal distribution on each one. Because of this departure from normality, non-parametric correlations (Spearman's rho) were calculated.

Table 2.1. Kolmogorov-Smirnov Test of Normality for measures

	Statistic	**df**	**Sig.**
BRCM	.223	69	.00
PAC	.177	69	.00
Zarit	.172	69	.00

Descriptives

Mean, Median, Range and Standard Deviations

A total of 193 questionnaires were sent out, and 69 caregivers participated in the research, with a response rate of 36%.

Descriptive statistics for the demographic variables are shown in Table 2.2. Forty seven of the 69 were female and 22 were male. The female participants were older and had spent a longer time caregiving. Of the 69 participants, 6 were recruited from the church support group, 21 were recruited through a local housing organisation, 16 were recruited from a local voluntary charity and 27 were recruited through the Alzheimer's Society. There were no returns from the NHS Trust sites. A total of 193 questionnaire packs had been sent out, meaning a response rate of 33%. Participants' average age was 71 years of age and 100% were of White British ethnicity and nationality.

Table 2.2 Mean, Median, Range and Standard Deviation for participant demographics

	Mean	**Median**	**Range (Years)**	**SD**
Age	71.54	71.00	57 - 84	7.69
Age (Male)	69.95	68.00	61 - 84	7.06
Age (Female)	72.28	73.00	57 - 89	7.93
Length of Time Caregiving	4.23	4.00	1 - 11	2.22
Length of Time Caregiving (Male)	3.95	4.00	1 - 9	1.96
Length of Time Caregiving (Female)	4.56	4.00	1 - 11	2.34

The means of the Zarit, PAC and BRCM were compared with means reported in earlier studies. Because only summary statistics and not the raw data were available for these studies, this had to be done using t-tests (two-tailed), despite the non-normal distribution of the data in the present study. Howell (2013) highlighted the robustness of t-tests for non-normal distributions, and therefore it was deemed that the data did not need to be transformed.

The mean of the BRCM (M = 60) was not significantly different from those reported for two samples in the original paper (Riley at al. 2013) (M = 64 and 59) ($t(118) = 0.19$; $p>.50$; $t(151) = .07$; $p>.50$). The mean of the PAC (M = 31) was also not significantly different from the one reported in the original paper (Tarlow et al. 2004) (M = 34) ($t(1,286) = 0.36$, $p>.50$). Previous studies have reported a wide range of means for the Zarit, e.g. Hebert et al. (2000) reported a mean of 22 in a

convenience sample drawn from the community in Canada, whereas Arai et al. (1997) reported a mean of 39 in a community sample in Japan.

Although there was a large difference between the mean in the Hebert paper and the one in the current study (22 vs. 45), this was not statistically significant (t (379) = 1.34; p>.10), which was due to the large standard deviations in the samples (16 for Hebert paper; 23 in current study). Arai et al., (1997) reported that the mean in their sample varied according to the age of the carer (M= 46 for those over 71; X = 37 for those below 50) and the presence of behavioural disturbances (X = 42 when present; X = 34 when absent). The relatively high mean of the current sample may reflect the fact that, compared to some other studies, the sample was somewhat older (mean age = 71) and may have had more experience of factors such as behavioural disturbances that increase burden.

Reliability

Cronbach's α's for the 23 BRCM items, the 9 PAC items and the 22 Zarit items were .96, .95 and .96 respectively. Therefore all three scales were found to be highly reliable.

The BRCM's Cronbach's α of .96 was similar to the original Cronbach's α of .95 as reported in the original paper (Riley et al. 2013). The PAC Cronbach's α of .95 compared well to the Cronbach's α of .89 reported in the original paper (Tarlow et al. 2004). The Zarit Cronbach's α of .96 was similar to the Cronbach's α of .93 reported in the paper by Seng et al. (2010).

Statistical Analyses

Correlations

In order to determine whether the data support the hypothesis that the caregivers' perception of the relationship is related to whether they experience higher levels of burden and more positive aspects of caregiving, the total scores on each of the measures were correlated. As the test of normality indicated that the data were not normally distributed, a non-parametric Spearman's Rho correlation coefficient was carried out (see Table 2.3).

Table 2.3. Spearman's Rho Correlations

	BRCM	**PAC**
PAC **Sig. (2-tailed)**	.765 .00	- -
Zarit **Sig. (2-tailed)**	-.785 .00	-.845 .00

The hypotheses were supported by the data. The correlations indicate a strong negative correlation between the BRCM and the Zarit, suggesting that as the perceived relationship continuity increases, the burden reported decreases. The correlations also indicate a strong positive correlation between the BRCM and the PAC, suggesting that as the perceived relationship continuity increases so do the perceived positive aspects of caregiving. The correlations indicate a strong negative correlation between the Zarit and the PAC, suggesting that as the reported burden increases, the reported positive aspects of caregiving decrease.

Additional Analyses

Demographics

The demographic variables were analysed to see if they were related to the three questionnaire measures. Spearman's rho was used to evaluate age and length of time caregiving; and an independent samples Kruskal-Wallis non-parametric ANOVA was used to evaluate the effects of gender and source of recruitment. Means for the three questionnaires broken down according to gender and source of recruitment are shown in Table 2.4.

Table 2.4. Descriptive statistics for the BRCM, the PAC and the Zarit broken down across gender and recruitment source

	Mean	Median	Range	SD	Inter-Quartile Range
BRCM (Total)	59.66	49.00	71.00	25.80	53.00
BRCM (Male)	60.50	52.00	71.00	27.68	54.50
BRCM (Female)	59.28	49.00	69.00	25.17	52.00
BRCM (Alzheimer's Society)	53.67	41.00	65.00	23.33	51.00
BRCM (Local Voluntary Charity)	53.71	48.00	62.00	21.37	28.50
BRCM (Housing Organisation)	64.45	85.00	66.00	28.85	55.75
BRCM (Church Group)	83.00	89.50	59.00	22.07	22.25
PAC (Total)	30.71	35.00	36.00	11.50	20.00
PAC (Male)	32.68	37.00	36.00	10.49	17.25
PAC (Female)	29.79	33.00	36.00	11.93	23.00
PAC (Alzheimer's Society)	26.19	23.00	36.00	11.38	22.00
PAC (Local Voluntary Charity)	34.36	36.50	28.00	8.63	9.75
PAC (Housing Organisation)	31.14	36.50	36.00	12.45	25.50
PAC (Church Group)	41.00	41.50	6.00	2.10	2.25
Zarit (Total)	45.93	44.00	73.00	22.62	41.00
Zarit (Male)	44.32	41.00	69.00	22.02	39.25
Zarit (Female)	46.68	50.00	73.00	23.10	41.00
Zarit (Alzheimer's Society)	54.67	64.00	67.00	23.33	46.00
Zarit (Local Voluntary Charity)	44.50	44.00	45.00	14.88	25.00
Zarit (Housing Organisation)	41.82	27.50	73.00	23.94	42.00
Zarit (Church Group)	25.00	20.50	29.00	11.37	10.25

Gender, age of the participant and length of time spent caregiving were not significantly related to any of the three questionnaire totals (see Appendix B). However, there was a significant difference between sources of recruitment on the Zarit (p = .003) and on the PAC (p = .011), though not on the BRCM (p = .091). Table 2.4 suggested that the reason for this was that those recruited from the Church support group scored higher on the BRCM and the PAC, and lower on the Zarit.

A further analysis was carried out comparing the participants from the Church support group with all other participants. There were significant differences on the Zarit (p = .007), the PAC (p = .013) and the BRCM (p = .026).

Readjusted Correlation for Recruitment Site

Because of these significant differences between the Church support group and the other participants, the correlations between the three questionnaire totals were recalculated with the scores of the Church support group omitted to see if the results were different (see Table 2.5).

Table 2.5. Spearman's Rho Correlation Coefficient (excluding church support group)

	BRCM	**PAC**
PAC	.750	-
Sig. (2-tailed)	.00	-
Zarit	-.765	-.834
Sig. (2-tailed)	.00	.00

The correlations indicate a strong negative correlation between the BRCM and the Zarit, r = -.77, p = 0.00, suggesting that as the perceived relationship continuity increases, the burden reported decreases. The correlations indicate a strong positive correlation between the BRCM and the PAC, r = .750, p = 0.00, suggesting that as the perceived relationship continuity increases so does the perceived positive aspects of caregiving. The correlations indicate a strong negative correlation

between the Zarit and the PAC, r = -.834, p = 0.00, suggesting that as the reported burden increases, the reported positive aspects of caregiving decreases.

Irrespective of the removal of the scores of those from the church group, the correlations were similar to those obtained in the initial analysis. This indicates that the church group scores did not alter or skew the data significantly.

DISCUSSION

This paper examined the relationship between relationship continuity, as measured by the BRCM and the impact of caregiving as measured by the PAC and the Zarit. The results of the statistical analysis supported the initial hypotheses made. The correlation coefficient showed a strong negative correlation between the BRCM and the Zarit, meaning that as the participants reported higher relationship continuity the amount of burden they reported decreased. The correlation coefficient also showed a strong positive correlation between the BRCM and the PAC, meaning that as the caregivers reported higher relationship continuity the amount of positive aspects of caregiving they reported also increased.

These findings are in agreement with previous claims, suggested in qualitative research, regarding the association between the caregivers' perception of the relationship and their experience of the caregiving role. In the study by Walters et al. (2010) he identified caregivers were more likely to feel entrapped and experience negative emotions in their caregiving role is they perceived it as discontinuous (Walters et al. 2010). Furthermore, Murray and Livingston (1998) and Steadmon, Tremont and Davies (2007) identified that relationship continuity determines how well a caregiver tolerated difficult or challenging behaviours associated with the dementia, which in turn can influence their experience of burden and negative emotions. Whilst relationship continuity can reduce burden, the results of this study also support the suggestions in the previous literature that it can also enhance the caregivers' experience. For example, Chesla, Martusan and Muwases (1994) suggested that relationship continuity is associated with more satisfaction, gratification and meaning from the

caregiving role. Similarly, Walter et al. (2010) found that caregivers who describe their relationship as more continuous are more likely to feel empathy towards their loved one with dementia.

Previously, research in this field has been qualitative; however this study provides quantitative evidence to strengthen the suggestion of the connection between relationship continuity and the caregivers' experience of the caregiving role that previous research has indicated.

An independent samples t-test found that the church group caregivers' scores on each of the measures were significantly different from the caregivers from other recruitment sites. The analysis indicated that those caregivers accessing support from the church group reported, on average, higher positive aspects of caregiving, lower experiences of burden and higher relationship continuity than those caregivers from other recruitment sites. This is consistent with previous research that has indicated that those caregivers of people with dementia who hold strong spiritual and religious beliefs report fewer depressive symptoms and burden (Heo, 2009) greater life satisfaction (Tix & Frazer, 1998) better perceived heath (Yeh et al. 2002) and more positive aspects of caregiving (Roff et al. 2004). A study by Herbert et al. (2007) used a large prospective sample to understand the relationship between religion and dementia caregiver well-being and mental health, following participants over an 18 month period. During this time, the amount of organised and non-organised religious activity was recorded as well as the importance of religious faith to the individual. The study found that those who engaged in either non-organised, such as prayer, or organised religious activities, such as attending church, reported less depressive symptoms and better perceived health. The study controlled for confounding variables such as the increase in social support associated with being a member of a church, and found that the relationship between religion and caregiver well-being was still the same. The study suggested that the role of religion is multifaceted in minimising the impact of the dementia on the caregiver. Herbert suggested that being a member of a church enables the caregiver to access people with similar values and provides the opportunity for the development of a shared understanding and reinterpretation of the suffering experienced into a divine plan, thereby reducing

distress experienced. Furthermore, Herbert suggests that God becomes a surrogate attachment figure to be turned to during times of distress, thus reducing the amount of separation anxiety they experience by the loss of their loved one. It may be, that in this sub-sample, other unique processes relating to religion, spirituality and faith were occurring that were not controlled for, meaning that this group were coping significantly better than caregivers from other recruitment sites.

The results of this study support the importance of studying the role of the relationship between the caregiver and the person with Dementia, and the impact the relationship may have on how well those involved cope with the challenges of dementia. For example, Steadman et al. (2007) found that when the caregiver reported greater satisfaction with the relationship, they also reported less burden, fewer negative emotional responses to Dementia-related behaviours, more effective communication skills and a greater ability to problem solve. The longitudinal study by Burgener and Twigg (2002) found that a better relationship predicted fewer declines in the person with dementia on a measure of general psychological well-being and on a scale that rated the use of problem solving in everyday settings.

Much of the research on family reactions to dementia has focused on attempting to explain variations in the degree of burden reported by the family carer. A recent systematic review on family burden by van der Lee at al. (2013) reviewed 56 papers. From this, the authors developed a multivariate model of subjective caregiver burden, which consisted of patient behavioural problems/mood disorders, patient self-care/need for support, patient cognitive function disorder, caregiver social functioning/support from others, caregiver health or psychological problems, caregiver competence and self-efficacy and caregiver coping/personality traits. Surprisingly, the relationship between caregiver and the care recipient did not factor in the multivariate model, indicating a lack of research investigating the association between burden and the relationship. Given the results of this study, and previous papers such as Steadman, Tremont and Davies (2007), the role of the relationship needs to be studied in the future and incorporated into models of caregiver burden

as a potential moderating factor. Indeed, the correlation between relationship continuity and burden observed in this study (-.785) was higher than the correlations between burden and many of the other factors in the model of van der Lee et al., suggesting that relationship factors may have a more substantial association with burden than many of the individual factors that have hitherto been the focus of so much research.

Based upon general caregiving literature a conceptual framework of positive aspects of caregiving in dementia was developed by Carbonneau, Caron and Desrosiers (2010). This framework identified three domains; the quality of the daily relationship between the caregiver and the care-recipient, the meaning of the caregiving role and the feelings of accomplishment. In this framework it suggests that by focussing on the relationship between the caregiver and care-recipient this can act as a mediator to reduce the stress and burden experienced as a result of the challenging behaviours on role captivity and depression (Lawrence, Tennstedt, & Assmann, 1998) as well as on caregivers' burden (Yates, Tennstedt, & Chang, 1999). Although this framework includes caregiver individual factors, such as self-efficacy, the emphasis is placed on the relationship between the caregiver and the care recipient. Given the large correlation between relationship continuity and positive aspects of caregiving in this study (.765), it not only provides support for this conceptual framework, but it also highlights the value of focussing on the relationship for future research and interventions for caregivers of those with dementia.

Previous quantitative research has used measures designed for the general population in order to assess the relationship between the caregiver and the person with Dementia (Ablitt et al., 2009). However, this study utilised the BRCM, a measure designed specifically to measure the relationship between the spousal caregiver of someone with Dementia. The high correlations observed in this study between the BRCM and the Zarit and the PAC, together with the high degree of internal reliability, suggest that the BRCM may be a useful measure for further investigations in this

area. Interestingly, the distribution of scores within the BRCM appeared bi-modal. This suggests that caregivers perceive their relationship as either continuous or discontinuous.

Limitations

As the study is questionnaire based and relies on self-report, it is subject to social desirability bias, meaning it is possible that participants are over-reporting 'positive' score and under-reporting 'negative' scores in order to protect their spouse and appear as a 'good carer'. It is also possible that participants may deny difficulties in their experience of caregiving, as they are not ready to acknowledge the full extent of the deterioration of the Dementia. It is common for people in the initial stages of grief to enter a denial stage, which protects them from emotional distress and grief (Kübler-Ross, 2005).

The correlational design of the study means that the direction of the relationship cannot be interpreted. Whilst it may be plausible that the caregivers' perception of the relationship influences and moderates the caregivers' experience of caregiving, it is also plausible that the experience of caregiving may influence the caregivers' perception of the relationship.

A further limitation of the study is the sampling issue. The study relied heavily on volunteer sampling from four distinct recruitment areas. It is unclear how representative they were of the carer population in dementia, and it is therefore unclear how much the findings can be generalised to this population. As all the participants were receiving support from an organisation in order to meet their needs as a caregiver, they may be functioning better than the general population, and therefore not truly representative. Furthermore, the study had no access to those individuals not in contact with services. Individuals who are not seeking support from services may either be functioning very well, or not functioning well at all, and therefore may represent a different type of caregiver to our sample. Similarly, different ethnic and cultural backgrounds were under-represented in the sample, and the wider applicability of the results is therefore unclear. In order to be more generalizable, the study required a larger randomised sample.

Another limitation is that the study employed a limited number of measures. Variables that might shed further light on, or that might be confounding, the association between relationship continuity, burden and the positive aspects of caregiving were not investigated. For example, Riley et al. (2013) recommended the use of a measure of pre-morbid functioning alongside the BRCM which they suggested is only valid if the spousal carer had a reasonable pre-morbid relationship with the person with dementia. A measure of pre-morbid functioning would also have been useful in order to investigate the possibility that the association between relationship continuity and burden/positive benefits from caregiving might be explained by their associations with the pre-morbid relationship. Another variable that might explain the association is the caregiver's personality style which can influence the way in which the caregiver perceives the relationship and experience of caregiving (Connell et al., 2001). However, it was thought that excessive demands on the time and goodwill of the participants that would be created by too many questionnaires, would have a negative impact on recruitment and data completion. Although figures were not available about how many people declined to take part in the study, the fact that there were no missing scores suggests that participants did not find participation too burdensome.

Another limitation of the study could have been the participants' interpretation of some of the items on the BRCM. Most of the items on the BRCM explicitly require the participant to compare the past and present (e.g. "He's a shadow of his former self"), but some items (specifically items 1, 5, 14, 15 and 19) do not make this comparison explicit (e.g. "He's in a world of his own most of the time"). Although it could be argued that, given the context (completing a questionnaire about how things have changed since the onset of the dementia), participants will make the comparison, it is possible that some would have endorsed a response such as "He's in a world of his own most of the time" prior to the onset of the dementia, endorse it now subsequent to the onset of the dementia, and so their response does not show discontinuity as the questionnaire assumes, but shows continuity. The high reliability of the BRCM suggests this is not a major issue, but one way of addressing the

issue would be to use a measure of the pre-morbid relationship so that relationships that had these negative dimensions prior to the onset of the dementia could be statistically controlled for.

Research Implications

Future research should focus on incorporating methods of controlling other variables that may have confounded the results and/or that may shed further light on the associations amongst the variables studied here, such as the pre-morbid relationship and the caregiver's personality. A larger and more representative sample would allow more effective investigation of the impact of demographic variables such as culture, length of caregiving and religion. A longitudinal design might also shed some light on whether the relationship between relationship continuity and burden/positive benefits is causal.

Clinical Implications

Bearing in mind the limitations, the results of the study suggest that it may be of benefit for carers to focus future interventions on the caregivers' sense of relationship continuity, and providing them with a way in which to maintain this sense of relationship continuity. It is possible that this will reduce the level of burden the caregiver experiences, and increase their experience of positive aspects of caregiving. The framework developed by Carbonneau, Caron and Desrosiers (2010) suggests that providing caregivers with ways to improve the quality of daily relationships this would be a useful way to support caregivers in reducing the level of burden experienced and increasing the experience of positive aspects of caregiving.

It has also been suggested that relationship continuity may have other beneficial effects, which further supports the argument that maintaining this should be a focus of intervention (Riley et al. 2013). For example, it has been suggested that relationship continuity is associated with a more empathic approach to caring (Walters et al. 2010), whilst relationship discontinuity can lead caregivers to depersonalise and objectify of their spouse, which could lead to restrictive and controlling caregiving styles (Walters et al. 2010; Lewis, 1998). Tom Kitwood coined the term

'malignant psychology' and argued that less empathic caring environments have a negative impact upon people with Dementia, and can accelerate the individual's deterioration. Helping the caregiver's maintain a sense of continuity in the identity of person with dementia and of their relationship may help create a more empathic caring environment, with benefits for both the caregiver and the person with dementia.

One option for helping maintain the sense of continuity is through an adaptation of some existing therapies. There is a strong evidence base for life review work (Haight et al. 2003) and reminiscence therapy (Woods, Spector, Jones, Orrell & Davies, 2009) for those individuals with dementia. These interventions are part of the NICE guidelines (National Institute for Health and Care Excellence, 2007) and are routinely carried out in group or individual sessions to help the individual with dementia maintain their individual sense of continuity and personhood. It is possible that these interventions could also be adapted with the goal of helping the caregiver to maintain a sense of continuity in the person with dementia and in the relationship. Interventions may need to be tailored to the stage of the diagnosis and the severity of the dementia, for example those in the initial diagnoses stage may require the retention of relationship continuity, whilst interventions designed for the restoration of continuity may be required for those where the person with dementia has deteriorated substantially.

It is recognised that there are many factors that may influence the well-being of caregivers and the person with dementia. The suggestion is not that interventions focus solely upon relational continuity, but that they are incorporated into a multi-modal model of care for people with Dementia and their caregivers.

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PAPER 3

Executive Summary

REACTIONS TO CARING FOR A SPOUSE OR PARTNER WITH DEMENTIA

Are perceptions of relationship continuity associated with emotional responses to providing care to a spouse with dementia?

REACTIONS TO CARING FOR A SPOUSE OR PARTNER WITH DEMENTIA

Are perceptions of relationship continuity associated with emotional responses to providing care to a spouse with dementia?

Background

In previous research, caregivers for individuals with dementia have reported both negative and positive outcomes. Negative outcomes have included feeling entrapped by the caregiving role, increased social isolation, higher levels of guilt, greater self-sacrifice, poorer physical health and increased feelings of burden and depression. On the other hand positive outcomes have included finding meaning and reward in the caregiving role, making a significant contribution to their loved one, being able to give something back to someone they love, feeling fulfilled, responsible, important or finding a sense of companionship and meaning within the relationship. This mixture of outcomes has led researchers to try to identify factors that determine whether caregivers experience positive or negative outcomes.

This study was interested in whether the relationship between the caregiver and the person with dementia determines whether the caregiver experiences positive or negative outcomes. Previous qualitative research (which involves interviewing a small number of research participants) has suggested that some caregivers perceive their relationship with the person with dementia as a continuation of a loving relationship with a person who, although changed, is essentially the same person. By contrast, other caregivers see the person with dementia as being a different person, and their relationship as being a very different relationship. Some qualitative studies have suggested that perceiving continuity may result in the caregiver experiencing more positive outcomes of the kind listed in the previous paragraph, but perceiving difference may result in more negative outcomes.

This study aimed to examine the association between the caregivers' perception of the relationship and their experience of caregiving using quantitative methods (using questionnaires and statistical analysis) to back up the evidence provided by the qualitative studies.

Method

Sixty-nine participants were recruited through voluntary organisations involved in supporting caregivers in their role. They were asked to complete a demographics sheet and three questionnaires including; 1) The Birmingham Relationship Continuity Measure (which is a measure of whether a caregiver perceives continuity or difference in their relationship with the person with dementia) (BRCM; Riley et al., 2013), 2) The Positive Aspect of Caregiving Scale (which measures some of the positive outcomes listed in the first paragraph) (PAC; Tarlow et al., 2004) and 3) The Zarit Burden Interview (which measures some of the negative outcomes listed in the first paragraph) (ZBI; Zarit, Reever & Bach-Peterson, 1980).

Results and Discussion

The study found that as participants rated higher levels of continuity in the relationship between themselves and their loved one with dementia, they experienced more positive aspects of caregivers and reduced levels of burden. The results provide quantitative support for the claims in previous qualitative research.

Further quantitative research is required, with larger and representative samples. These studies should also control for other variables, such as the quality of the premorbid relationship prior to the onset of dementia. A longitudinal study may be beneficial in being able to establish a causal link.

Interventions should be designed to focus on the relationship between the caregiver and the person with dementia, as not only will this improve caregiver well-being, but will also have an impact upon the quality of care provided and subsequent well-being of the person with dementia.

APPENDIX A

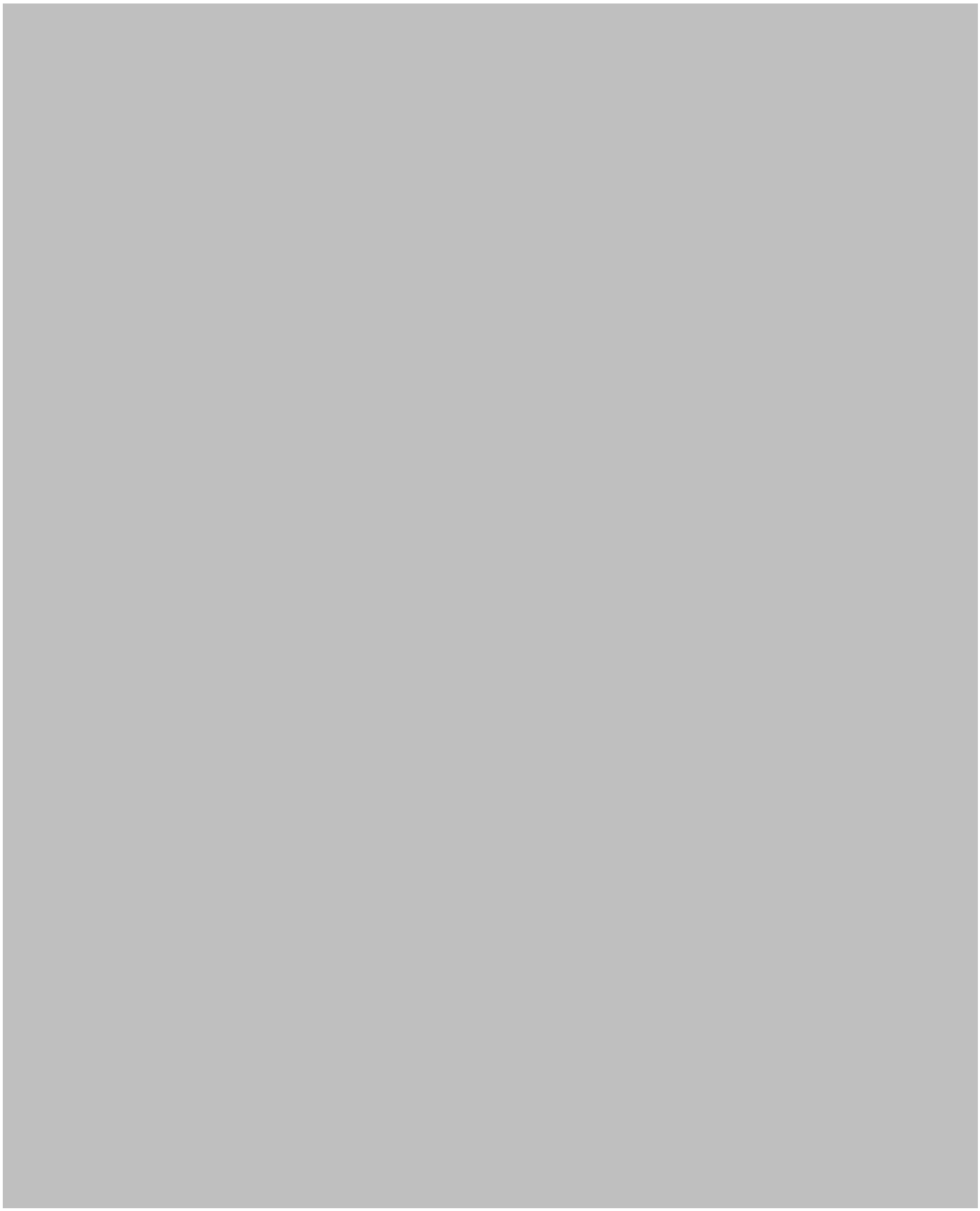
Adapted Downs and Black (1998) Quality Framework

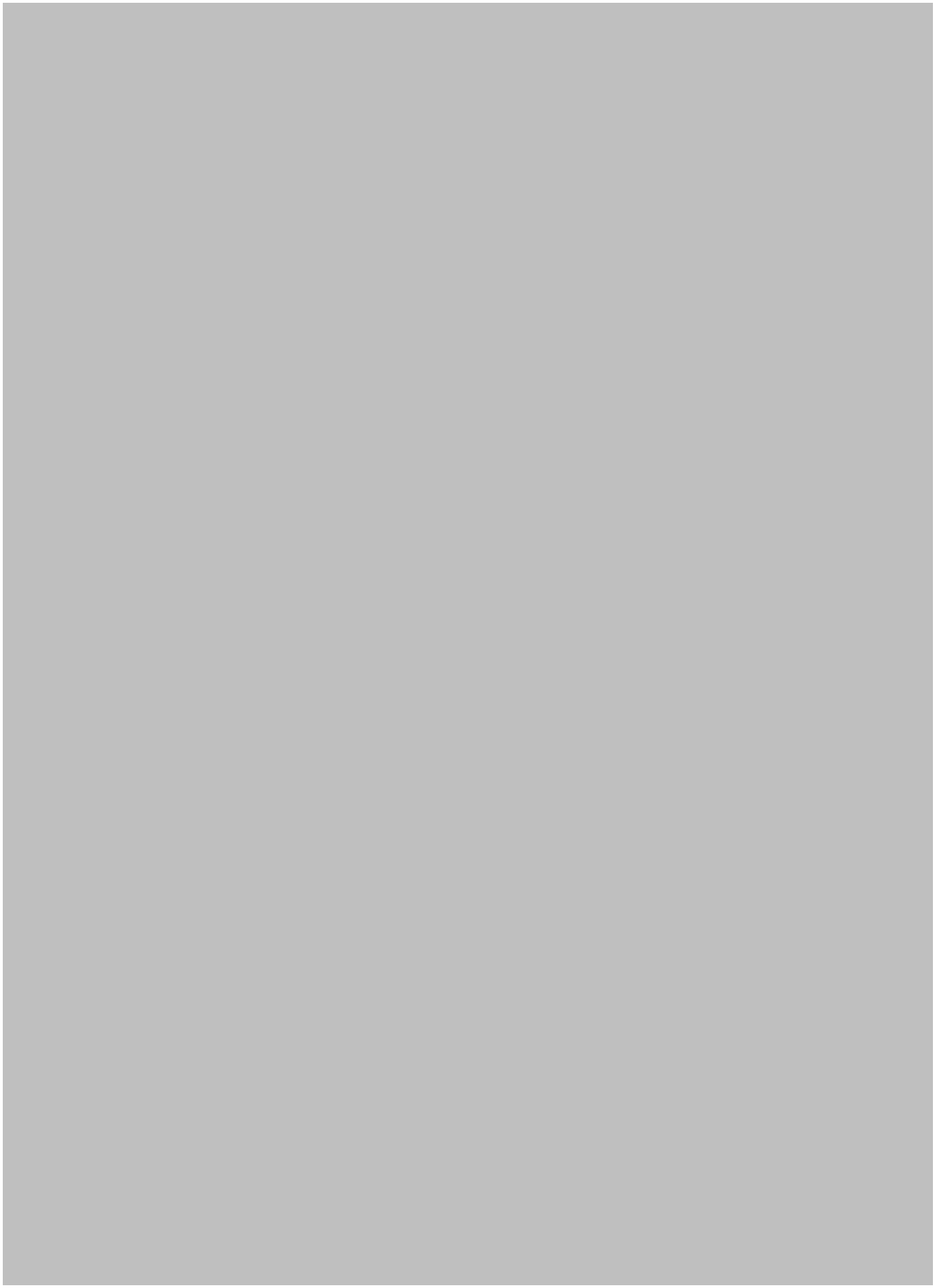
Reference				
Background Information				
Hypothesis/aim/objective				
Is the hypothesis/aim/objective of study clearly described?	Yes	1	No	0
Main outcomes to be measured				
Are the main outcomes to be measured clearly described in the Introduction/Methods section?	Yes	1	No	0`
Participants				
Are the characteristics of the patients included in the study clearly described? (i.e. Inclusion/Exclusion clearly defined)	Yes	1	No	0`
Methodology/Design				
Are the interventions of interest clearly described?	Yes	1	No	0`

Are the distributions of principal confounders in each of the subjects to be compared clearly defined?	Yes 2	Partially 1	No 0
Results/Statistical Analysis			
Are the main findings of the study clearly described?	Yes 1	No 0`	
Does the study provide estimates of the random variability in the data for the main outcomes?	Yes 1	No 0`	
Have all important adverse events that may be a consequence of the intervention been reported?	Yes 1	No 0`	
Have the characteristic of patients lost to follow-up been described?	Yes 1	No 0`	
Have actual probability values been reported for the main outcomes (except where the probability value is less than 0.00)1?	Yes 1	No 0`	
External Validity			
Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Yes 1	No/Unable to Determine 0`	
Were the subjects who were prepared to participate representative of the entire population from which they were recruited?	Yes 1	No/Unable to Determine 0	
Were the staff, places, facilities where patients were treated, representative of the treatment the majority of patients receive?	Yes 1	No/Unable to Determine 0	
Internal Validity - bias			
Was an attempt made to blind study subjects to the intervention they have received?	Yes 1	No/Unable to Determine 0	
Was an attempt made to blind those measuring the main outcomes of the intervention?	Yes 1	No/Unable to Determine 0	
If any of the results of the study were based on 'data dredging' was this made clear?	Yes 1	No/Unable to Determine 0	
In trials/cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	Yes 1	No/Unable to Determine 0	
Were the statistical tests used to assess the main outcomes appropriate?	Yes 1	No/Unable to Determine 0	
Was compliance with the intervention/s reliable?	Yes 1	No/Unable to Determine 0	
Were the main outcome measure accurate (valid	Yes 1	No/Unable to	

and reliable)?		Determine 0
Internal Validity – confounding (selection bias)		
Were the patients in different intervention groups or were the cases and controls recruited from the same population?	Yes 1	No/Unable to Determine 0
Were study subjects in different intervention groups or were the cases and controls recruited over the same period of time?	Yes 1	No/Unable to Determine 0
Were study subjects randomised to intervention group?	Yes 1	No/Unable to Determine 0
Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	Yes 1	No/Unable to Determine 0
Was there adequate adjustment for confounding in the analysis from which main findings were drawn?	Yes 1	No/Unable to Determine 0
Were losses of patients to follow-up taken into account?	Yes 1	No/Unable to Determine 0
Power		
Did the paper report a power analysis?	Yes 1	No/Unable to Determine 0
Was the sample size to achieve power achieved?	Yes 1	No/Unable to Determine 0
If no power analysis indicated, did the study meet the cut-off for detecting a medium or large effect?	Yes 1	No/Unable to Determine 0
Discussion/Findings/Implications		

APPENDIX B





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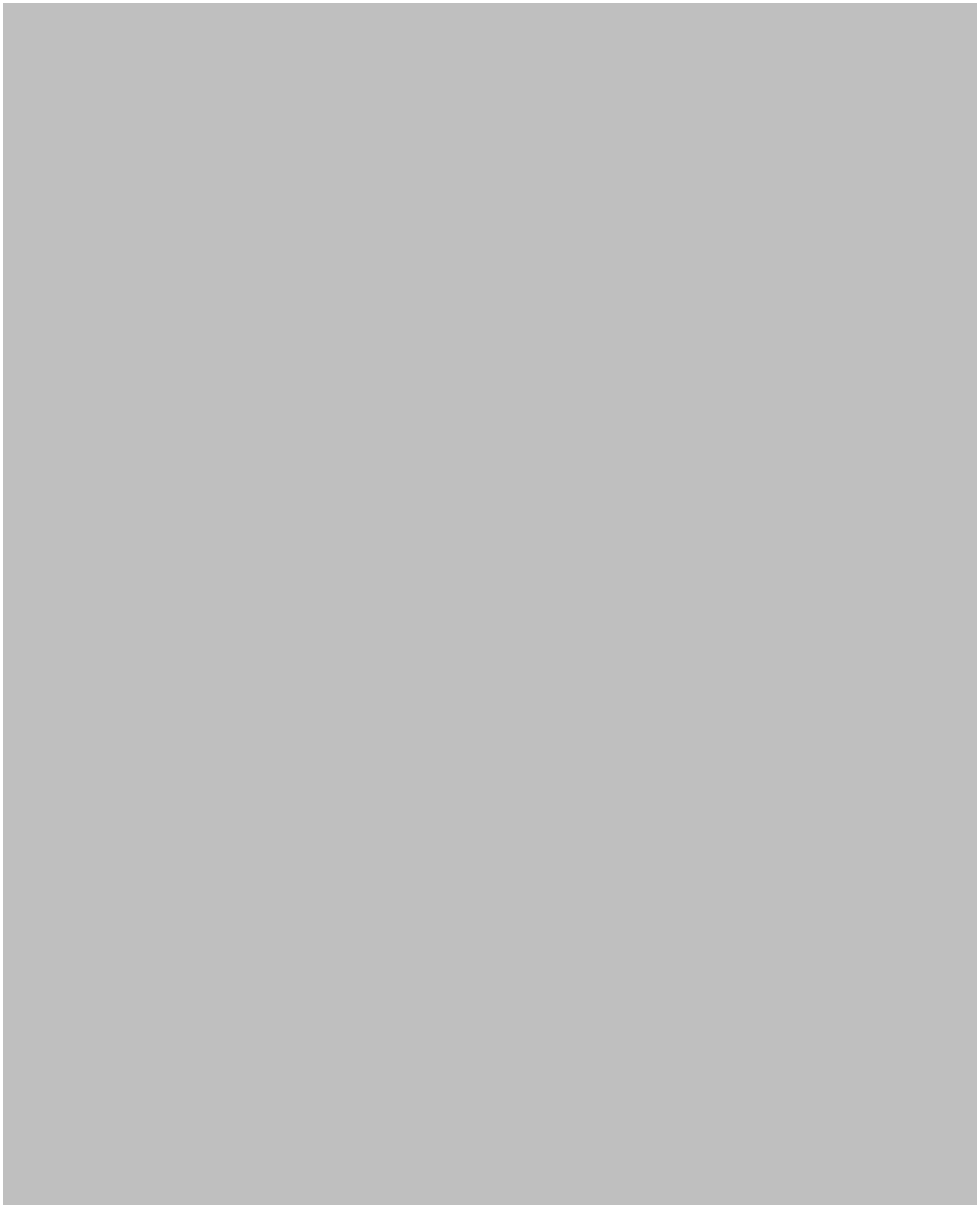
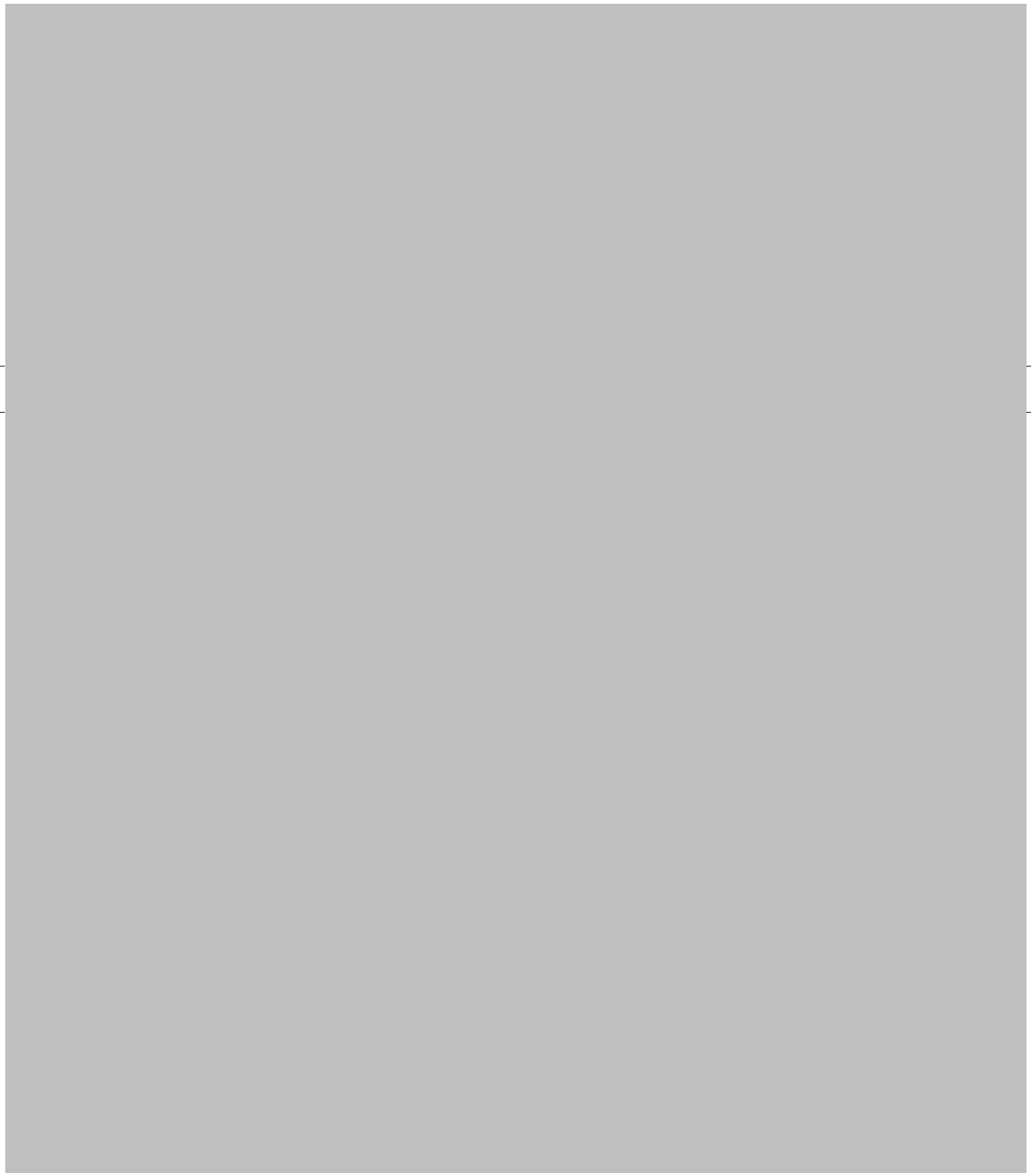




Consent for Contact

Research Project: Reactions to caring for a spouse or partner with dementia

Consent for Chief Investigator to Contact

I have read the advertisement about this research and hereby give consent for Laura Evans (Chief Investigator) to contact me. ☐

My contact details are:

Home phone: _____

Mobile: _____

Or, if you prefer me to contact you by e-mail,

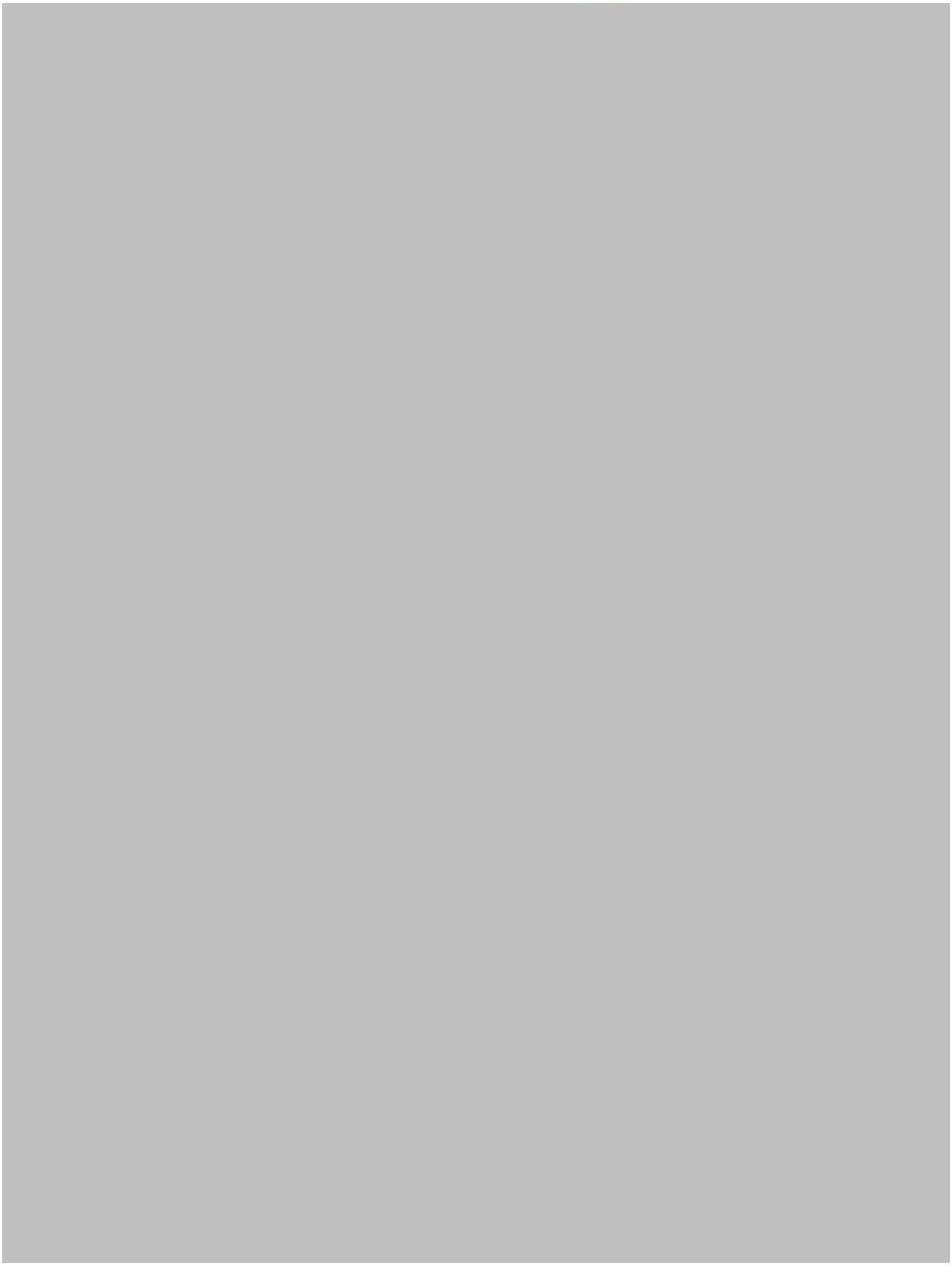
e-mail : _____

Print Name: _____

Signed: _____

Date: _____

Covering Letter



Participant Information Booklet

Research Title: Reactions to caring for a spouse or partner with dementia

Name of Researcher: Laura Evans, Trainee Clinical Psychologist

PARTICIPANT INFORMATION LEAFLET

My name is Laura Evans. I would like to invite you to take part in a research study. This research is being carried out as part of my training course in clinical psychology. The research is being supervised and monitored by the University of Birmingham. It has also has been reviewed and approved by Solihull Research Ethics Committee.

Before you decide whether you would like to take part, it is important for you to know and understand why the research is being done and what it will involve.

Please read the following information carefully and talk it over with your family if you want to. Take your time deciding whether or not this is something that you would like to do.

If you have any further questions or would like more information, you can ring me on or e-mail me on

What is the purpose of this study?

The research focuses on the experiences of people who are looking after a spouse or partner who has dementia. There have been some suggestions in previous research that the caregivers' views about their relationship with the person with dementia may have an effect on how they react to being a caregiver. This study aims to investigate the link between the caregivers' perception of the relationship and how they react to their role as a caregiver

Why am I being asked to take part?

You are being asked to take part because you live with, and provide care for, a husband, wife or partner who has dementia. It is also important that you lived with this person for at least 5 years before they were diagnosed with dementia.

Do I have to take part?

No. It is entirely your choice whether you take part or not. If you decide not to take part, this will not affect the care and support that you or your spouse/partner receive in any way. Even if you agree at first, you can change your mind at any time and withdraw from the study without giving any explanation. You can also withdraw the information you provide at any time up until the point when I write up the research project. If you wish to do this, you should contact me using the e-mail or phone number on the first page of this leaflet.

What will I have to do if I take part?

If you agree to take part in the study, you will complete 3 questionnaires plus a demographics sheet. One of these will ask you for some information about yourself (e.g. your age); one will ask questions about how you feel about your relationship with your spouse/partner (e.g. "It doesn't feel like a partnership anymore"; one will ask about the benefits that carers sometimes experience from caregiving (e.g. " Providing help to him/her has enabled me to appreciate life more"); and the final one will ask about the challenges that carers sometimes experience (e.g. "Do you feel embarrassed over your relative's behaviour?").

These questionnaires should take no more than 30 minutes to complete.

What are the possible benefits of taking part?

There are no direct benefits to yourself in taking part. However, we hope that this research will lead to a better understanding of the needs of carers in your situation, and so enable services to provide better support to carers in the future. By taking part, you could help bring about these improvements.

What are the possible disadvantages of taking part?

Some people may find some of the items on the questionnaires upsetting because they are asking about your relationship and about how you feel about providing care. Please do not take part if you think this will be too upsetting for you. If you get too upset when answering the questionnaires, you do not have to complete them and you can withdraw from the study. You may also want to make use of the support services whose contact details are given at the end of this leaflet. If you want assistance in contacting these services, please let me know and I will help you to get in touch with them.

Will my taking part in the study be kept confidential?

Confidentiality is assured. No one will be able to access the information that you provide except myself, my academic supervisor and individuals authorized by the University to conduct a research audit. When not in use, all the paperwork will be kept in a locked filing cabinet in a locked office at the University. I will also put the scores from the questionnaires onto a computer file. This computer file will be kept on password-protected computer accounts at the University to which only myself and

my academic supervisor have access; and it will not contain any personal information that would allow you to be identified.

What happens next?

I will telephone you a few days after you have received this leaflet, and ask whether you wish to take part. You will be given at least 48 hours to make up your mind before I contact you. When I contact you, you will be given the chance to ask any further questions you might have about the research.

If you decide not to take part, then this will be the end of the matter and I will not contact you again.

If you decide you would like to take part, I will send you the questionnaires and a consent form to complete and return in a pre-paid envelope that I will also send you. If you have difficulty with completing the questionnaires for whatever reason (e.g. because writing is difficult for you), please let me know and we can arrange to meet up so that I can help to complete the questionnaires. If the questionnaires and consent form are not returned within 3 weeks, I will phone you again to remind you about them. I will make only one such phone call, and will not make any attempt to contact you after that.

Can I find out what the results of the study were?

If you would like to receive a brief report that summarizes the results of my research, then there is a space on the consent form where you can enter your address. I will send you the summary once the research is complete.

What support is available for me if I am finding it difficult to cope?

The Alzheimer's Society is a useful source of support for those who are caring for someone with Dementia, as well as the person with Dementia themselves. They offer a range of activities and meetings where you can meet people in a similar situation to yourself. To find out more information and to find the nearest society to you, contact:

Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

Phone: 020 7423 3500
Fax: 020 7423 3501
e-mail: enquiries@alzheimers.org.uk

Or contact them on their helpline on: 0300 222 11 22

If you do find that you are struggling with the caregiving experience, with your permission, I can also support you in accessing your G.P. It may be worthwhile to arrange an appointment with your G.P. who can offer additional support if you feel this may be helpful. Furthermore, with your permission, I will notify your spouse's keyworker that you may need some additional support.

Caregiving can be a very stressful experience, and if I feel you might need a little more help or support I will have a chat with you about my concerns and encourage you to access other services that may benefit you. In this circumstance I will need to notify your spouse's keyworker as well as your G.P. However, you will be involved in this decision making process.

What if I want to complain?

If for any reason, you are not satisfied with how the research was conducted, please contact the name provided below, who will take further action.

What if I need more information?

If you require any further information about the study, or have any concerns you wish to raise, or require any further advice or support, you can ring me on or e-mail me on and I will get back to you as soon as possible.

Informed Consent Form

Consent Form

Research Title: Reactions to caring for a spouse or partner with dementia

Name of Researcher: Laura Evans, Trainee Clinical Psychologist

Please place your initials in the box

I confirm that I have read and understand the information sheet for the above study and have had the chance to ask questions.	☐
I understand that I am free to withdraw from the study at any time, without giving a reason.	☐
I understand that all of the information gathered will remain private and confidential.	☐
I understand that the information I provide during my participation may be seen by individuals authorized to conduct a research audit. I give permission for these individuals to view this information.	☐
I agree that by partaking in this study, if there are concerns regarding my own mental health and well-being that my G.P. can be contacted and my spouse's keyworker be informed. A discussion with me will take place prior to this.	☐
I agree to take part in this study	☐

_____		
Name of participant	Date	Signature
_____		
Researcher	Date	Signature

If you would like to receive a copy of a final summary of the research project when it is completed, please write down your address below:

Address:_____

PLEASE RETURN THIS FORM ALONG WITH THE COMPLETED QUESTIONNAIRES IN THE ENVELOPE PROVIDED

Demographics Sheet

Demographic Sheet

Please do not write your name on this form. It will be stored separately from any other information that you complete during this study and will not be linked with your responses in any way. This information will give us an accurate description of who is taking part in the study.

For the following items, please select the *one* response that is most descriptive of you or fill in the blank as appropriate.

Gender: Male ❑ Female ❑

Age: _____

Ethnicity:

White

White British ❑

White Irish ❑

White (Other) _____.

Black

Black Caribbean ❑

Black African ❑

Black (Other) _____.

Asian

Indian ❑

Pakistani ❑

Bangladeshi ❑

Chinese ❑

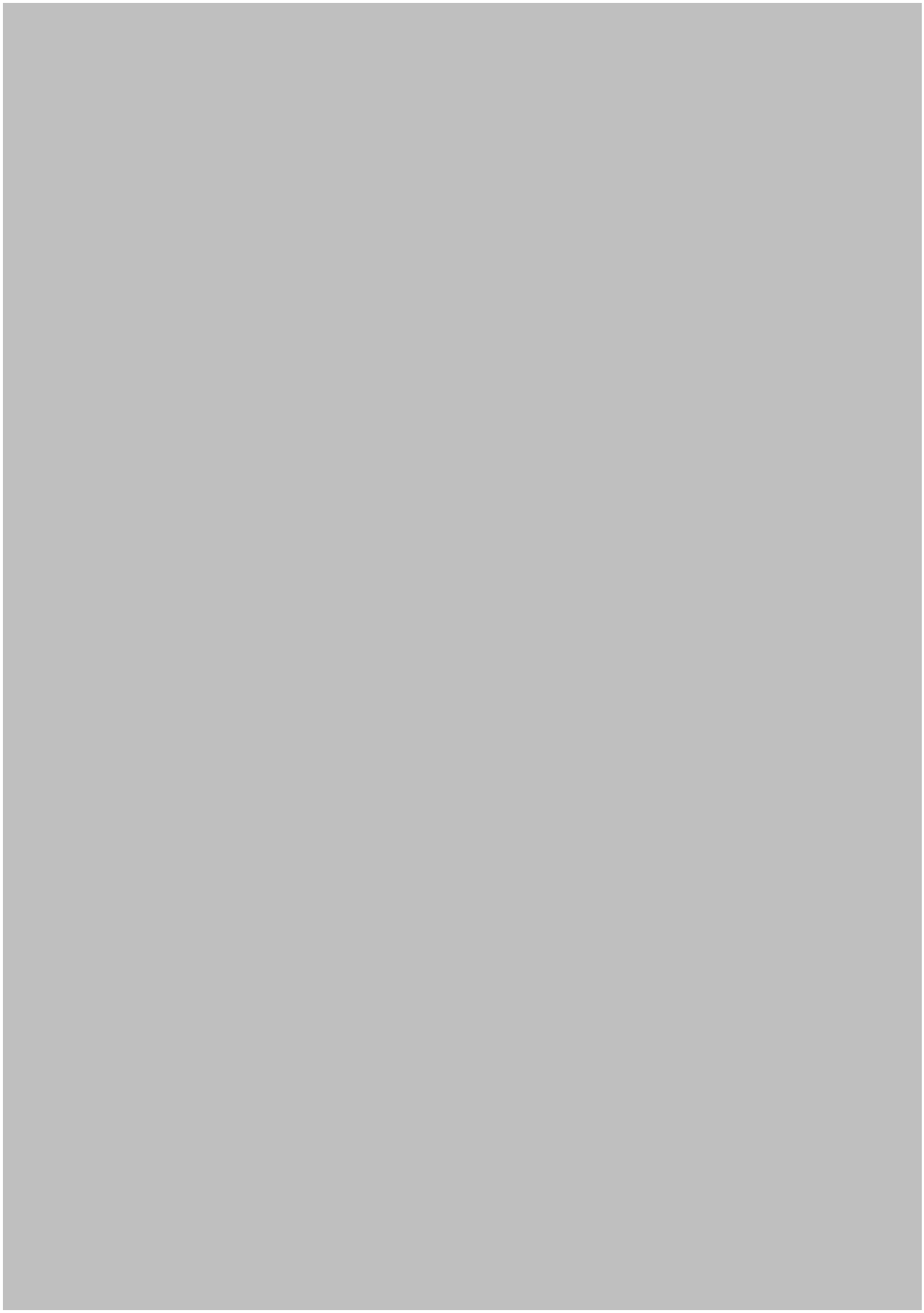
Asian (Other) _____.

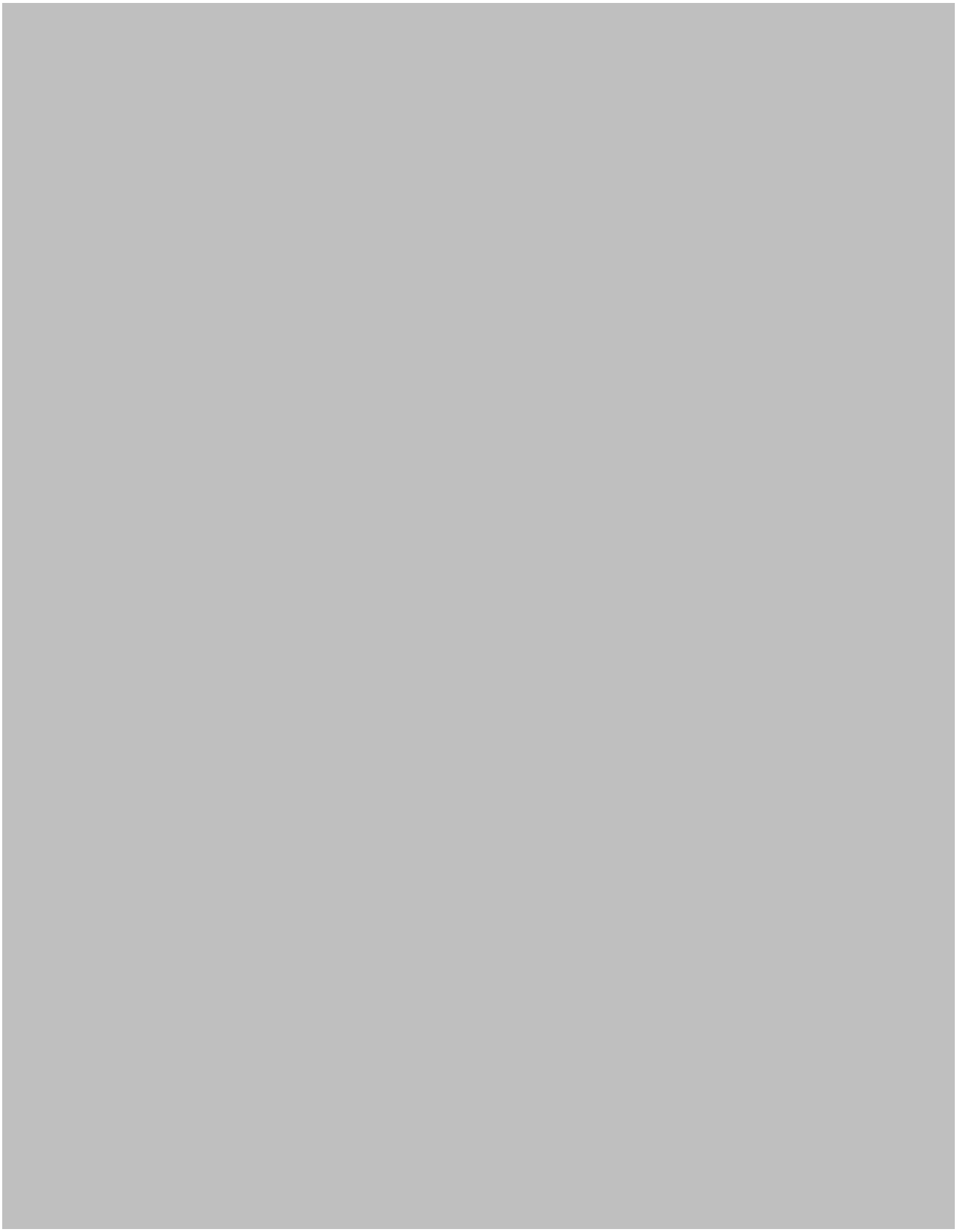
Mixed

Please State _____.

Other _____.

Birmingham Relationship Continuity Measure (Riley et al., 2013)





THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Positive Aspects of Caregiving Scale (Tarlow et al., 2004)

ositive Aspects of Caregiving

Some caregivers say that, despite all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over some of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements.

Providing help to my spouse has…	**Disagree a lot**	**Disagree a little**	**Neither Agree or Disagree**	**Agree a little**	**Agree a lot**	**Unknown**	**Refused**
Made me feel more useful	1	2	3	4	5	-3	-4
Made me feel good about myself	1	2	3	4	5	-3	-4
Made me feel needed	1	2	3	4	5	-3	-4
Made me feel appreciated	1	2	3	4	5	-3	-4
Made me feel important	1	2	3	4	5	-3	-4
Made me feel strong and confident	1	2	3	4	5	-3	-4

Enabled me to appreciate life more	1	2	3	4	5	-3	-4
Enabled me to develop a more positive attitude towards life	1	2	3	4	5	-3	-4
Strengthened my relationship with others	1	2	3	4	5	-3	-4

Thank you for completing this questionnaire.

The Zarit Burden Interview

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	**Score**
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
Total Score (out of 88)						

SPSS Data Output

Kolmogorov-Smirnov

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
BRCMTotal	.223	69	.000	.825	69	.000
ZaritTotal	.177	69	.000	.902	69	.000
PACTotal	.172	69	.000	.883	69	.000

a. Lilliefors Significance Correction

Descriptives

Descriptives

			Statistic	Std. Error
BRCMTotal	Mean		59.6667	3.10547
	95% Confidence Interval for Mean	Lower Bound	53.4698	
		Upper Bound	65.8635	
	5% Trimmed Mean		59.5008	
	Median		49.0000	
	Variance		665.431	
	Std. Deviation		25.79596	
	Minimum		27.00	
	Maximum		98.00	
	Range		71.00	
	Interquartile Range		53.00	
	Skewness		.214	.289
	Kurtosis		-1.747	.570
ZaritTotal	Mean		45.9275	2.72358
	95% Confidence Interval for Mean	Lower Bound	40.4927	
		Upper Bound	51.3623	
	5% Trimmed Mean		45.2834	
	Median		44.0000	
	Variance		511.833	
	Std. Deviation		22.62372	
	Minimum		15.00	
	Maximum		88.00	
	Range		73.00	
	Interquartile Range		41.00	

	Skewness	.214	.289
	Kurtosis	-1.410	.570
PACTotal	Mean	30.7101	1.38422
	95% Confidence Interval for Mean — Lower Bound	27.9480	
	95% Confidence Interval for Mean — Upper Bound	33.4723	
	5% Trimmed Mean	31.1006	
	Median	35.0000	
	Variance	132.209	
	Std. Deviation	11.49821	
	Minimum	9.00	
	Maximum	45.00	
	Range	36.00	
	Interquartile Range	20.00	
	Skewness	-.478	.289
	Kurtosis	-1.286	.570

Descriptives

	Area			Statistic	Std. Error
BRCMTotal	Alzheimers Socitey	Mean		53.6667	4.48994
		95% Confidence Interval for Mean	Lower Bound	44.4375	
			Upper Bound	62.8959	
		5% Trimmed Mean		53.0617	
		Median		41.0000	
		Variance		544.308	
		Std. Deviation		23.33040	
		Minimum		27.00	
		Maximum		92.00	
		Range		65.00	
		Interquartile Range		51.00	
		Skewness		.680	.448
		Kurtosis		-1.210	.872
	BUDS	Mean		53.7143	5.71236
		95% Confidence Interval for Mean	Lower Bound	41.3735	
			Upper Bound	66.0551	
		5% Trimmed Mean		53.0159	
		Median		48.0000	
		Variance		456.835	
		Std. Deviation		21.37370	

		Minimum		29.00	
		Maximum		91.00	
		Range		62.00	
		Interquartile Range		28.50	
		Skewness		.792	.597
		Kurtosis		-.636	1.154
	Accord	Mean		64.4545	6.15166
		95% Confidence Interval for Mean	Lower Bound	51.6615	
			Upper Bound	77.2476	
		5% Trimmed Mean		64.9495	
		Median		85.0000	
		Variance		832.545	
		Std. Deviation		28.85386	
		Minimum		27.00	
		Maximum		93.00	
		Range		66.00	
		Interquartile Range		55.75	
		Skewness		-.227	.491
		Kurtosis		-2.053	.953
	Church	Mean		83.0000	9.01110
		95% Confidence Interval for Mean	Lower Bound	59.8362	
			Upper Bound	106.1638	
		5% Trimmed Mean		84.6111	
		Median		89.5000	
		Variance		487.200	
		Std. Deviation		22.07261	
		Minimum		39.00	
		Maximum		98.00	
		Range		59.00	
		Interquartile Range		22.25	
		Skewness		-2.198	.845
		Kurtosis		5.057	1.741
ZaritTotal	Alzheimers Socitey	Mean		54.6667	4.48962
		95% Confidence Interval for Mean	Lower Bound	45.4381	
			Upper Bound	63.8952	
		5% Trimmed Mean		54.6996	
		Median		64.0000	
		Variance		544.231	
		Std. Deviation		23.32875	

		Minimum		21.00	
		Maximum		88.00	
		Range		67.00	
		Interquartile Range		46.00	
		Skewness		-.248	.448
		Kurtosis		-1.605	.872
	BUDS	Mean		44.5000	3.97762
		95% Confidence Interval for Mean	Lower Bound	35.9069	
			Upper Bound	53.0931	
		5% Trimmed Mean		44.8333	
		Median		44.0000	
		Variance		221.500	
		Std. Deviation		14.88288	
		Minimum		19.00	
		Maximum		64.00	
		Range		45.00	
		Interquartile Range		25.00	
		Skewness		-.314	.597
		Kurtosis		-.877	1.154
	Accord	Mean		41.8182	5.10480
		95% Confidence Interval for Mean	Lower Bound	31.2022	
			Upper Bound	52.4342	
		5% Trimmed Mean		40.7980	
		Median		27.5000	
		Variance		573.299	
		Std. Deviation		23.94366	
		Minimum		15.00	
		Maximum		88.00	
		Range		73.00	
		Interquartile Range		42.00	
		Skewness		.414	.491
		Kurtosis		-1.470	.953
	Church	Mean		25.0000	4.64040
		95% Confidence Interval for Mean	Lower Bound	13.0715	
			Upper Bound	36.9285	
		5% Trimmed Mean		24.0556	
		Median		20.5000	
		Variance		129.200	
		Std. Deviation		11.36662	
		Minimum		19.00	

		Maximum		48.00	
		Range		29.00	
		Interquartile Range		10.25	
		Skewness		2.357	.845
		Kurtosis		5.631	1.741
PACTotal	Alzheimers Socitey	Mean		26.1852	2.18974
		95% Confidence Interval for Mean	Lower Bound	21.6841	
			Upper Bound	30.6863	
		5% Trimmed Mean		26.0947	
		Median		23.0000	
		Variance		129.464	
		Std. Deviation		11.37824	
		Minimum		9.00	
		Maximum		45.00	
		Range		36.00	
		Interquartile Range		22.00	
		Skewness		.120	.448
		Kurtosis		-1.311	.872
	BUDS	Mean		34.3571	2.30767
		95% Confidence Interval for Mean	Lower Bound	29.3717	
			Upper Bound	39.3426	
		5% Trimmed Mean		34.9524	
		Median		36.5000	
		Variance		74.555	
		Std. Deviation		8.63452	
		Minimum		15.00	
		Maximum		43.00	
		Range		28.00	
		Interquartile Range		9.75	
		Skewness		-1.254	.597
		Kurtosis		.613	1.154
	Accord	Mean		31.1364	2.65416
		95% Confidence Interval for Mean	Lower Bound	25.6167	
			Upper Bound	36.6560	
		5% Trimmed Mean		31.5758	
		Median		36.5000	
		Variance		154.981	
		Std. Deviation		12.44912	

		Minimum		9.00	
		Maximum		45.00	
		Range		36.00	
		Interquartile Range		25.50	
		Skewness		-.480	.491
		Kurtosis		-1.510	.953
	Church	Mean		41.0000	.85635
		95% Confidence Interval for Mean	Lower Bound	38.7987	
			Upper Bound	43.2013	
		5% Trimmed Mean		41.1111	
		Median		41.5000	
		Variance		4.400	
		Std. Deviation		2.09762	
		Minimum		37.00	
		Maximum		43.00	
		Range		6.00	
		Interquartile Range		2.25	
		Skewness		-1.755	.845
		Kurtosis		3.657	1.741

Non-parametric Correlations

Correlations

			Age	LengthofTimeCaregiving	BRCMTotal	ZaritTotal	PACTotal
Spearman's rho	Age	Correlation Coefficient	1.000	.173	.025	-.079	.053
		Sig. (2-tailed)	.	.154	.838	.516	.663
		N	69	69	69	69	69
	LengthofTimeCaregiving	Correlation Coefficient	.173	1.000	-.058	.044	-.082
		Sig. (2-tailed)	.154	.	.635	.720	.505
		N	69	69	69	69	69
	BRCMTotal	Correlation Coefficient	.025	-.058	1.000	-.785**	.765**
		Sig. (2-tailed)	.838	.635	.	.000	.000
		N	69	69	69	69	69
	ZaritTotal	Correlation Coefficient	-.079	.044	-.785**	1.000	-.845**
		Sig. (2-tailed)	.516	.720	.000	.	.000
		N	69	69	69	69	69
	PACTotal	Correlation Coefficient	.053	-.082	.765**	-.845**	1.000
		Sig. (2-tailed)	.663	.505	.000	.000	.
		N	69	69	69	69	69

**. Correlation is significant at the 0.01 level (2-tailed).

Kruskal-Wallis – Area

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of BRCMTotal is the same across categories of Area.	Independent-Samples Kruskal-Wallis Test	.091	Retain the null hypothesis.
2	The distribution of ZaritTotal is the same across categories of Area.	Independent-Samples Kruskal-Wallis Test	.003	Reject the null hypothesis.
3	The distribution of PACTotal is the same across categories of Area.	Independent-Samples Kruskal-Wallis Test	.011	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Kruskal-Wallis – Gender

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of BRCMTotal is the same across categories of Gender.	Independent-Samples Kruskal-Wallis Test	.643	Retain the null hypothesis.
2	The distribution of ZaritTotal is the same across categories of Gender.	Independent-Samples Kruskal-Wallis Test	.897	Retain the null hypothesis.
3	The distribution of PACTotal is the same across categories of Gender.	Independent-Samples Kruskal-Wallis Test	.409	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Kruskal-Wallis – Church vs. No Church

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of BRCMTotal is the same across categories of ChurchvNonchurch.	Independent-Samples Kruskal-Wallis Test	.026	Reject the null hypothesis.
2	The distribution of ZaritTotal is the same across categories of ChurchvNonchurch.	Independent-Samples Kruskal-Wallis Test	.007	Reject the null hypothesis.
3	The distribution of PACTotal is the same across categories of ChurchvNonchurch.	Independent-Samples Kruskal-Wallis Test	.013	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.